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# **Parent and patient perspective of fatal and near-fatal asthma.**



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Submitted for the degree of Doctor of Philosophy

The University of Edinburgh

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## **Declaration**

I declare that this thesis presented for the degree of Doctor of Philosophy of Population Health Sciences, has

- i)        been composed entirely by myself
- ii)       been solely the result of my own work
- iii)      not been submitted for any other degree or professional qualification

Ann McMurray

# **Abstract**

## **Introduction**

Asthma is one of the most common long term conditions, typically affecting 1 in 11 children and 1 in 12 adults within the UK. Although asthma attacks are common, near-fatal asthma attacks and asthma deaths are rare. Statistics are available worldwide for asthma deaths, but the true incidence of near-fatal asthma (NFA) is unknown as there is no current definition to use as a benchmark. Factors which contribute to near-fatal and fatal asthma attacks have been identified in literature and confidential enquires. To date, however, there are no known studies that have examined these attacks from the patient and parent/carer perspective.

## **Aims/ objectives of the PhD**

The overarching aim of this study was to define NFA and identify potential modifiable behaviours to reduce the risk of NFA and an asthma-related death. This PhD study was sub-divided into two components:

1. A scoping review, an asthma guideline review and an eDelphi study to identify a consensus definition of NFA
2. Qualitative interviews to explore parents' and young adults' perspectives of fatal and near-fatal asthma.

Component one aims were to:

- Gain an international clinical consensus name and definition for a 'critical asthma attack' to enable the frequency of defined attacks to be measured, against which future interventions can be trialled to reduce these and asthma deaths.
- Utilise the consensus name and definition to identify participants for the NFA qualitative study

The aims for the scoping review and asthma guideline review were included as chapter aims.

Component two aims were to:

- Identify key time-critical experiences of those who have experienced NFA (or their parents), or parents of those whose child died of asthma, that may provide a window of opportunity to seek help.
- Understand family circumstances and behaviours that may place children and young people at greater risk of asthma death/near fatal asthma.
- To understand the long-term psychosocial consequences of NFA.
- To use these findings to inform key stakeholders such as education, primary care, severe asthma registries and emergency service responses, in order to reduce the risks of fatal and near-fatal asthma and provide appropriate support for children and young people (CYP), young adults and their families.

In order to achieve these aims, interviews were carried out to give the opportunity to parents of children and young adults who have experienced NFA attacks and bereaved parents of children who have suffered a fatal attack, to describe their experience.

## **Methods and findings**

The programme of work was sub-divided into two components.

Component One included a scoping review, asthma guideline review and an eDelphi.

The term 'critical asthma attack' was used within this component as the name for the attack was evolved.

### **Scoping review and asthma guidelines review**

Following the methodology proposed by Arksey and O'Malley, with adaptations by Levac et al., and the Joanna Briggs Institute, a five stage scoping review was conducted to identify names, definitions, objective measurements, clinical features

and parent/ perspective of a critical asthma attack, which could result in an asthma death. To supplement the findings of the scoping review, a review of asthma guidelines available worldwide was also conducted using the same research questions as the scoping review. Results from both reviews were used to inform the initial eDelphi questionnaire.

## **eDelphi**

I recruited an international expert panel to gain consensus for a clinical name and definition for a critical asthma attack. Overall, 104 participants from 25 countries completed all three rounds of the study. Participants worked across the fields of respiratory, critical care and emergency department medicine, caring for both adults and children. Near-fatal asthma was the agreed name for the event and was defined as,

*“A near-fatal asthma attack occurs in a person who is exhausted, with severe dyspnoea, unable to speak, with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies. This is associated with hypoxaemia, hypercarbia and a falling pH”.*

This definition was used to recruit participants to the near-fatal asthma studies.

## **Parent and patient interviews**

A total of 24 single, in-depth semi-structured interviews were conducted. Five young people and 12 parents, which included two couples, who had been affected by near-fatal asthma attacks and seven parents affected by asthma deaths participated. Interviews were recorded and transcribed verbatim. Interviews were analysed using thematic analysis from a modified constructivist grounded theory approach, assisted by NVivo pro version 11 to manage the data.

Trusting your intuition, following an asthma plan and calling emergency services were identified as key time critical opportunities, which emerged within both the fatal and near fatal asthma interviews. When considering behaviours and circumstances the attitude of ‘it’s just asthma’ in conjunction with knowledge and awareness of asthma

management and the impact of previous attacks, were identified in both studies. The long lasting social and psychological effects post NFA were identified as long-term consequence, with an impact on both the person who had experienced the attack and the wider family.

## **Discussion and conclusion**

To the best of my knowledge this is the first time parents and young adults have had the opportunity to share their perspective of fatal and NFA attacks. The definition of near-fatal asthma, which has been agreed by international consensus, once published, could be used in future studies against which interventions could be measured. There were areas of current knowledge with regards to risk factors for a NFA attack or asthma death that could be enhanced. These included: a previous NFA attack; previous admission to hospital; heavy/ overuse of SABA; psychological impact and clinicians' knowledge. The novel findings of this study that should be implemented into care and policy include: the power of intuition; the effect of hypoxaemia on decision making; the normalisation of asthma; and lack of awareness that asthma attacks can result in asthma death. These findings were mapped into the social-ecological model used as a framework for this study. This model considered individual, interpersonal, community, organisational and public policy factors and how important implementing change across multiple levels of the model at the same time are required to improve outcomes for children and young people affected by asthma. The findings from both studies could be applied to educational packages, emergency service algorithms and severe asthma registries, with an aim to reduce asthma attacks and asthma deaths.

## **Lay summary**

There are 5.4 million people in the UK who have asthma. Even though there are inhalers and medications to treat people with asthma, every 10 seconds someone with asthma in the UK has an asthma attack. Although most attacks can be treated with the blue inhaler and spacer or a nebuliser there is a type of asthma attack which is so bad it can make you stop breathing or stop your heart. If it's not treated at the right time the person can die. This is sometimes called a near-fatal asthma attack, but sometimes clinicians use other names. Doctors and nurses have given their point of view on what happens when someone has a near-fatal asthma attack or when someone dies of an asthma attack. No one has asked young adults or parents/carers of children, young people and young adults for their point of view. We feel this is very important and will help give better care and help prevent serious asthma attacks and asthma deaths.

## **Aims**

- To agree a name and explain the meaning of the name used to describe the very severe asthma attack, with doctors across the world.
- To use the agreed name and explanation of the very severe attack to recruit parents and young adults to the interviews.
- To find out from parents or young adults what had happened at the time of the severe attack and to try and see if there could be ways to stop this happening in the future.
- To find out from parents and young adults about how asthma is managed at home and to work out if there is advice that could be given to help prevent severe asthma attacks in the future.
- To find out more about the long-term effects of a severe asthma attack on mental health and day to day activities.



## **Methods and results**

I looked at research papers on near-fatal asthma and found features such as how someone looked when they were having this attack, or results of tests. I also looked at the asthma guidelines around the world for similar information. These results were used to make up a questionnaire which was sent to doctors who work with patients who would have these type of asthma attacks. 104 doctors from 25 countries took part in three questionnaires and in the end, they all agreed to call this type of attack near-fatal asthma and they agreed on how to explain it.

I used the explanation of near-fatal asthma to recruit parents and young adults (16 – 24 years) to take part in the interviews. They told me their story of what happened. They told me how they felt and how they managed the attack. They also told me about other things they felt may have had an effect on this attack, such as things that were happening at home, or other health problems.

Parents whose child (up to age 24 years) had died because of an asthma attack, also told me their story. They told me what happened and what they feel was different about this fatal attack compared to previous attacks their child had experienced.

## **Conclusion**

This is the first time parents and young adults have had a chance to tell their story of a near-fatal attack or their child's death due to asthma. We have been able to agree, with doctors across the world, to call this very severe asthma attack, a near-fatal asthma attack. We have also been able to explain what this means. This name and explanation could be used in the future by healthcare professionals and researchers. There were risk factors we already knew about for near-fatal attacks and asthma deaths however parents and young adults have given us more information on things such as: previous admissions to hospital; the use of the blue inhaler; mental health and the knowledge of doctors and nurses. They also told us new information which

included: 'gut instinct'; making a decision when the oxygen level in the body is low; people's attitude towards asthma; and not knowing that some asthma attacks can cause death. Using the information learned from these stories will help work out ways to give better care and may help prevent serious asthma attacks and asthma deaths.

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# Table of Contents

|                                                  |             |
|--------------------------------------------------|-------------|
| <b>DECLARATION.....</b>                          | <b>I</b>    |
| <b>ABSTRACT .....</b>                            | <b>II</b>   |
| INTRODUCTION .....                               | II          |
| AIMS/ OBJECTIVES OF THE PHD .....                | II          |
| METHODS AND FINDINGS .....                       | III         |
| SCOPING REVIEW AND ASTHMA GUIDELINES REVIEW..... | III         |
| EDELPHI.....                                     | IV          |
| PARENT AND PATIENT INTERVIEWS.....               | IV          |
| DISCUSSION AND CONCLUSION .....                  | V           |
| <b>LAY SUMMARY .....</b>                         | <b>VI</b>   |
| AIMS .....                                       | VI          |
| METHODS AND RESULTS.....                         | VII         |
| CONCLUSION .....                                 | VII         |
| <b>ACKNOWLEDGEMENTS .....</b>                    | <b>IX</b>   |
| <b>TABLE OF CONTENTS .....</b>                   | <b>XI</b>   |
| <b>LIST OF TABLES.....</b>                       | <b>XIX</b>  |
| <b>LIST OF FIGURES .....</b>                     | <b>XXII</b> |
| <b>LIST OF BOXES .....</b>                       | <b>XXIV</b> |
| <b>LIST OF APPENDICES.....</b>                   | <b>XXIV</b> |
| <b>CONTRIBUTIONS TO SCIENCE .....</b>            | <b>XXVI</b> |
| ORAL PRESENTATIONS .....                         | XXVI        |
| POSTER PRESENTATIONS .....                       | XXVI        |

|                                                                  |          |
|------------------------------------------------------------------|----------|
| ABBREVIATIONS .....                                              | XXVII    |
| <b>1 CHAPTER ONE – OVERVIEW OF THESIS .....</b>                  | <b>1</b> |
| 1.1 OVERVIEW OF THIS PHD .....                                   | 1        |
| 1.2 ASTHMA UK CENTRE FOR APPLIED RESEARCH .....                  | 1        |
| 1.3 RESEARCH ENVIRONMENT AND AVAILABLE EXPERTISE .....           | 1        |
| 1.4 PATIENT PUBLIC INVOLVEMENT (PPI) .....                       | 3        |
| 1.5 NOTE ON TERMINOLOGY .....                                    | 4        |
| 1.6 OUTLINE OF THE THESIS CHAPTERS .....                         | 4        |
| <b>2 CHAPTER TWO: INTRODUCTION.....</b>                          | <b>6</b> |
| 2.1 OVERVIEW OF ASTHMA .....                                     | 6        |
| 2.2 DIAGNOSIS OF ASTHMA .....                                    | 7        |
| 2.3 ASTHMA PHENOTYPES .....                                      | 9        |
| 2.4 ASTHMA MEDICATION.....                                       | 11       |
| 2.4.1 SABA/ Relievers .....                                      | 12       |
| 2.4.2 Inhaled corticosteroids (ICS).....                         | 13       |
| 2.4.3 Combination inhalers.....                                  | 14       |
| 2.4.4 Leukotriene receptor antagonists (LTRA) .....              | 15       |
| 2.4.5 Other therapies.....                                       | 15       |
| 2.4.6 Medications used for acute asthma attacks .....            | 16       |
| 2.5 ASTHMA TRIGGERS.....                                         | 19       |
| 2.6 SOCIOCULTURAL FACTORS THAT IMPACT ON ASTHMA MANAGEMENT ..... | 19       |
| 2.6.1 Ethnicity.....                                             | 19       |
| 2.6.2 Parental quality of life .....                             | 20       |
| 2.7 ASTHMA ATTACK VERSUS EXACERBATION OF ASTHMA.....             | 21       |
| 2.8 PATHOPHYSIOLOGY OF AN ASTHMA ATTACK .....                    | 22       |
| 2.9 NEAR-FATAL ASTHMA (NFA).....                                 | 23       |

|          |                                                                       |           |
|----------|-----------------------------------------------------------------------|-----------|
| 2.9.1    | Pathophysiology of a NFA attack .....                                 | 23        |
| 2.9.2    | Near-fatal asthma phenotypes .....                                    | 24        |
| 2.9.3    | Pharmacological and non-pharmacological management of NFA .....       | 25        |
| 2.9.4    | Risks associated with a NFA attack .....                              | 26        |
| 2.10     | FATAL ASTHMA .....                                                    | 26        |
| 2.11     | AIMS AND OBJECTIVES OF THIS PHD .....                                 | 34        |
| 2.12     | UNDERPINNING THEORY IN QUALITATIVE RESEARCH .....                     | 35        |
| 2.12.1   | Socio-ecological model .....                                          | 36        |
| 2.13     | SUMMARY AND NEXT STEPS. ....                                          | 37        |
| <b>3</b> | <b>CHAPTER THREE – SCOPING REVIEW .....</b>                           | <b>39</b> |
| 3.1      | INTRODUCTION .....                                                    | 39        |
| 3.2      | AIMS .....                                                            | 39        |
| 3.3      | METHODS .....                                                         | 39        |
| 3.3.1    | Stage 1: Identifying the research questions .....                     | 41        |
| 3.3.2    | Stage 2: Identifying relevant studies .....                           | 42        |
| 3.3.3    | Search strategies and databases .....                                 | 43        |
| 3.3.4    | Stage 3: Study selection .....                                        | 44        |
| 3.3.5    | Stage 4: Charting the data .....                                      | 44        |
| 3.3.6    | Stage 5: Collating, summarising and reporting the results .....       | 45        |
| 3.4      | RESULTS .....                                                         | 45        |
| 3.4.1    | Geography of studies included .....                                   | 47        |
| 3.4.2    | Name of the critical asthma attack .....                              | 48        |
| 3.4.3    | Definitions of name used to describe the critical asthma attack. .... | 48        |
| 3.4.4    | Objective measurements .....                                          | 56        |
| 3.4.5    | Clinical features .....                                               | 65        |
| 3.4.6    | Parent/ carer/ patient perspective .....                              | 71        |

|          |                                                                                                                                       |           |
|----------|---------------------------------------------------------------------------------------------------------------------------------------|-----------|
| 3.4.7    | Other key features .....                                                                                                              | 71        |
| 3.5      | DISCUSSION.....                                                                                                                       | 72        |
| 3.6      | STRENGTHS AND LIMITATIONS .....                                                                                                       | 76        |
| 3.7      | CONCLUSION .....                                                                                                                      | 78        |
| 3.8      | SUMMARY AND NEXT STEPS .....                                                                                                          | 78        |
| <b>4</b> | <b>CHAPTER FOUR - COMPARING ASTHMA ATTACK MANAGEMENT<br/>WITHIN ASTHMA GUIDELINES WORLDWIDE AND THE GINA ASTHMA<br/>STRATEGY.....</b> | <b>79</b> |
| 4.1      | INTRODUCTION.....                                                                                                                     | 79        |
| 4.2      | ASTHMA GUIDELINES .....                                                                                                               | 79        |
| 4.3      | AIMS.....                                                                                                                             | 81        |
| 4.4      | METHODS .....                                                                                                                         | 81        |
| 4.5      | ANALYSIS.....                                                                                                                         | 83        |
| 4.6      | RESULTS .....                                                                                                                         | 83        |
| 4.7      | THE CATEGORISATION OF ASTHMA SEVERITY.....                                                                                            | 85        |
| 4.7.1    | Objective measurements .....                                                                                                          | 85        |
| 4.7.2    | Clinical features .....                                                                                                               | 89        |
| 4.7.3    | Activities of daily living .....                                                                                                      | 91        |
| 4.7.4    | Near fatal Asthma (NFA) .....                                                                                                         | 92        |
| 4.8      | DISCUSSION.....                                                                                                                       | 93        |
| 4.9      | STRENGTHS AND LIMITATIONS .....                                                                                                       | 95        |
| 4.10     | CONCLUSION .....                                                                                                                      | 95        |
| 4.11     | SUMMARY AND NEXT STEPS .....                                                                                                          | 96        |
| <b>5</b> | <b>CHAPTER 5: DEFINING NEAR FATAL ASTHMA: AN INTERNATIONAL<br/>EDELPHI STUDY.....</b>                                                 | <b>97</b> |
| 5.1      | INTRODUCTION.....                                                                                                                     | 97        |



|          |                                                               |            |
|----------|---------------------------------------------------------------|------------|
| 5.2      | AIMS.....                                                     | 99         |
| 5.3      | METHODS .....                                                 | 99         |
| 5.4      | ETHICS .....                                                  | 103        |
| 5.5      | RECRUITMENT OF EXPERTS.....                                   | 103        |
| 5.6      | POPULATION .....                                              | 105        |
| 5.7      | CONSENT .....                                                 | 105        |
| 5.8      | eDELPHI ROUNDS ONE AND TWO .....                              | 106        |
| 5.9      | eDELPHI ROUND THREE .....                                     | 108        |
| 5.10     | RESULTS .....                                                 | 108        |
| 5.11     | ROUND ONE RESULTS, NAME OF THE EVENT .....                    | 119        |
| 5.12     | THEMATIC ANALYSIS OF FREE TEXT DATA .....                     | 119        |
| 5.12.1   | Interchangeable terminology.....                              | 120        |
| 5.12.2   | Current Understanding .....                                   | 120        |
| 5.12.3   | Impact of variables .....                                     | 121        |
| 5.12.4   | Emotive terminology .....                                     | 121        |
| 5.13     | ROUND ONE RESULTS OF OTHER VARIABLES .....                    | 121        |
| 5.14     | ROUND TWO RESULTS .....                                       | 129        |
| 5.15     | ROUND THREE RESULTS .....                                     | 131        |
| 5.15.1   | Sub-analysis of objective measurements.....                   | 133        |
| 5.16     | DISCUSSION.....                                               | 134        |
| 5.17     | STRENGTHS AND LIMITATIONS OF THE STUDY .....                  | 136        |
| 5.18     | CONCLUSION .....                                              | 139        |
| 5.19     | SUMMARY AND NEXT STEPS .....                                  | 140        |
| <b>6</b> | <b>CHAPTER 6: METHODS – QUALITATIVE INTERVIEW STUDY .....</b> | <b>141</b> |
| 6.1      | INTRODUCTION.....                                             | 141        |
| 6.2      | ARRIVING AT A TOPIC AND STUDY DESIGN.....                     | 141        |

|        |                                                     |     |
|--------|-----------------------------------------------------|-----|
| 6.3    | REFLEXIVITY .....                                   | 142 |
| 6.3.1  | Reflecting on my role in the research process ..... | 142 |
| 6.4    | QUALITATIVE RESEARCH .....                          | 143 |
| 6.5    | THE RESEARCH PARADIGM .....                         | 147 |
| 6.5.1  | Axiology, ontology and epistemology .....           | 148 |
| 6.6    | METHODOLOGY .....                                   | 151 |
| 6.6.1  | Grounded theory .....                               | 152 |
| 6.7    | STUDY POPULATION .....                              | 154 |
| 6.8    | INCLUSION AND EXCLUSION CRITERIA .....              | 155 |
| 6.8.1  | Near-fatal interviews - inclusion criteria .....    | 155 |
| 6.8.2  | Fatal attack interviews - inclusion criteria .....  | 156 |
| 6.8.3  | Near-fatal interviews – exclusion criteria .....    | 156 |
| 6.8.4  | Fatal attack interviews – exclusion criteria .....  | 156 |
| 6.9    | SAMPLING .....                                      | 157 |
| 6.10   | RECRUITMENT .....                                   | 157 |
| 6.10.1 | Near-fatal asthma study .....                       | 158 |
| 6.10.2 | Fatal asthma study .....                            | 159 |
| 6.11   | CONSENT .....                                       | 160 |
| 6.12   | INTERVIEWS .....                                    | 161 |
| 6.13   | TRANSCRIBING .....                                  | 162 |
| 6.14   | ANALYTIC PROCESS .....                              | 163 |
| 6.15   | CODING AND IDENTIFICATION OF THEMES .....           | 164 |
| 6.16   | MEMO WRITING .....                                  | 165 |
| 6.17   | NVIVO .....                                         | 166 |
| 6.18   | ETHICAL CONSIDERATIONS .....                        | 166 |
| 6.18.1 | Fatal asthma .....                                  | 166 |
| 6.18.2 | Near-fatal asthma .....                             | 167 |

|          |                                                                                                                                                 |            |
|----------|-------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| 6.18.3   | Interviewer safety and distress .....                                                                                                           | 168        |
| 6.18.4   | Participant safety and distress .....                                                                                                           | 168        |
| 6.18.5   | Transcriber distress .....                                                                                                                      | 169        |
| 6.18.6   | Disclosure.....                                                                                                                                 | 169        |
| 6.19     | ETHICAL APPROVAL .....                                                                                                                          | 170        |
| 6.20     | SUMMARY AND NEXT STEPS .....                                                                                                                    | 170        |
| <b>7</b> | <b>CHAPTER SEVEN: FINDINGS FROM THE INTERVIEWS WITH PARENTS<br/>AND YOUNG ADULTS ON THEIR EXPERIENCE OF A NEAR-FATAL ASTHMA<br/>ATTACK.....</b> | <b>171</b> |
| 7.1      | INTRODUCTION.....                                                                                                                               | 171        |
| 7.2      | YOUNG ADULT PARTICIPANTS .....                                                                                                                  | 171        |
| 7.3      | PARENT PARTICIPANTS .....                                                                                                                       | 172        |
| 7.4      | THEMES.....                                                                                                                                     | 174        |
| 7.4.1    | Key time-critical experiences .....                                                                                                             | 174        |
| 7.4.2    | The power of intuition .....                                                                                                                    | 175        |
| 7.4.3    | Self-management strategies.....                                                                                                                 | 177        |
| 7.4.4    | Family circumstances and behaviours .....                                                                                                       | 180        |
| 7.4.5    | Knowledge and awareness.....                                                                                                                    | 183        |
| 7.4.6    | Psychological impact of a near fatal asthma attack.....                                                                                         | 188        |
| 7.4.7    | Uncertainty of the future .....                                                                                                                 | 190        |
| 7.5      | CONCLUSION .....                                                                                                                                | 193        |
| 7.6      | SUMMARY AND NEXT STEPS .....                                                                                                                    | 193        |
| <b>8</b> | <b>CHAPTER EIGHT: FINDINGS FROM THE INTERVIEWS WITH PARENTS ON<br/>THEIR EXPERIENCE OF THEIR CHILD’S FATAL ASTHMA ATTACK. ....</b>              | <b>194</b> |
| 8.1      | INTRODUCTION.....                                                                                                                               | 194        |
| 8.2      | PARTICIPANTS.....                                                                                                                               | 194        |

|           |                                                                |            |
|-----------|----------------------------------------------------------------|------------|
| 8.3       | THEMES.....                                                    | 197        |
| 8.3.1     | Key time critical experiences .....                            | 197        |
| 8.3.2     | The power of intuition .....                                   | 198        |
| 8.3.3     | Emergency management.....                                      | 199        |
| 8.3.4     | Potentially modifiable behaviours and circumstances. ....      | 202        |
| 8.3.5     | It's just asthma.....                                          | 204        |
| 8.3.6     | Knowledge and awareness.....                                   | 205        |
| 8.3.7     | Impact of previous attacks .....                               | 210        |
| 8.4       | CONCLUSION .....                                               | 212        |
| 8.5       | SUMMARY AND NEXT STEPS .....                                   | 213        |
| <b>9</b>  | <b>CHAPTER NINE: DISCUSSION.....</b>                           | <b>214</b> |
| 9.1       | INTRODUCTION.....                                              | 214        |
| 9.2       | SUMMARY OF FINDINGS .....                                      | 214        |
| 9.3       | KEY TIME CRITICAL EXPERIENCES.....                             | 215        |
| 9.3.1     | Power of intuition .....                                       | 215        |
| 9.3.2     | Emergency management.....                                      | 216        |
| 9.4       | BEHAVIOURS AND CIRCUMSTANCES .....                             | 221        |
| 9.4.1     | Knowledge and awareness.....                                   | 221        |
| 9.4.2     | Impact of previous attacks .....                               | 227        |
| 9.4.3     | Psychological impact of attacks .....                          | 229        |
| 9.5       | INFLUENCES ON OUTCOMES .....                                   | 230        |
| 9.5.1     | Scenario One .....                                             | 231        |
| 9.6       | APPLYING THE SOCIO-ECOLOGICAL MODEL .....                      | 233        |
| 9.7       | STRENGTHS AND LIMITATIONS AND METHODOLOGICAL REFLECTIONS ..... | 238        |
| 9.7.1     | Reflections on methods. ....                                   | 238        |
| <b>10</b> | <b>SUMMARY AND RECOMMENDATIONS.....</b>                        | <b>246</b> |

|                         |                                                                               |            |
|-------------------------|-------------------------------------------------------------------------------|------------|
| 10.1                    | SUMMARY OF PHD THESIS .....                                                   | 246        |
| 10.2                    | RECOMMENDATIONS.....                                                          | 250        |
| 10.2.1                  | For individuals with asthma.....                                              | 250        |
| 10.2.2                  | For families, friends and social groups caring for individuals with<br>asthma | 250        |
| 10.2.3                  | Community services .....                                                      | 251        |
| 10.2.4                  | For professionals and clinical services.....                                  | 251        |
| 10.2.5                  | Organisations .....                                                           | 252        |
| 10.2.6                  | For policy makers .....                                                       | 252        |
| 10.2.7                  | For research .....                                                            | 253        |
| 10.3                    | FINAL THOUGHT. ....                                                           | 254        |
| <b>REFERENCES .....</b> |                                                                               | <b>255</b> |
| <b>APPENDICES .....</b> |                                                                               | <b>281</b> |

## List of tables

|                                                                                                                  |           |
|------------------------------------------------------------------------------------------------------------------|-----------|
| <b>Table 1: patients at risk of developing near-fatal or fatal asthma .....</b>                                  | <b>7</b>  |
| <b>Table 2: Classification of asthma phenotypes in children.....</b>                                             | <b>10</b> |
| <b>Table 3: Combination inhalers available for children and young people .....</b>                               | <b>14</b> |
| <b>Table 4: Medications used for problematic Severe Asthma .....</b>                                             | <b>16</b> |
| <b>Table 5: Bronchodilators and their route of administration .....</b>                                          | <b>17</b> |
| <b>Table 6 : Near-fatal asthma phenotypes.....</b>                                                               | <b>24</b> |
| <b>Table 7: Key factors affecting children and young people .....</b>                                            | <b>28</b> |
| <b>Table 8: Summary of Confidential Enquiries in UK 1982 – 2020 .....</b>                                        | <b>31</b> |
| <b>Table 9: The five stage scoping review process .....</b>                                                      | <b>41</b> |
| <b>Table 10: Geography of included studies. ....</b>                                                             | <b>47</b> |
| <b>Table 11: Names and definitions used to represent critical asthma attack in<br/>chronological order. ....</b> | <b>50</b> |

|                                                                                                      |            |
|------------------------------------------------------------------------------------------------------|------------|
| <b>Table 12: Objective measurements identified within the scoping review in chronological order.</b> | <b>59</b>  |
| <b>Table 13: Clinical features identified within the scoping review.</b>                             | <b>68</b>  |
| <b>Table 14: Parent and patient perspective of a critical asthma attack.</b>                         | <b>71</b>  |
| <b>Table 15: Other key features of a critical asthma attack.</b>                                     | <b>72</b>  |
| <b>Table 16: Asthma guideline according to year, country, population and source of guideline.</b>    | <b>84</b>  |
| <b>Table 17: Number of guidelines according to continent.</b>                                        | <b>84</b>  |
| <b>Table 18: SpO<sub>2</sub> according to level of asthma attack severity.</b>                       | <b>86</b>  |
| <b>Table 19: PEFR (% predicted) according to level of asthma attack severity.</b>                    | <b>87</b>  |
| <b>Table 20: HR (beats per minute) by level of asthma attack severity.</b>                           | <b>87</b>  |
| <b>Table 21: RR (breaths per minute) by level of asthma attack severity.</b>                         | <b>87</b>  |
| <b>Table 22: BP by level of asthma attack severity.</b>                                              | <b>88</b>  |
| <b>Table 23: Pulsus paradoxus (mmHg) by level of asthma attack severity.</b>                         | <b>88</b>  |
| <b>Table 24: PaCO<sub>2</sub> (mmHg/ kPa) by level of asthma attack severity.</b>                    | <b>89</b>  |
| <b>Table 25: PaO<sub>2</sub> (mmHg/ kPa) by level of asthma attack severity.</b>                     | <b>89</b>  |
| <b>Table 26: Accessory muscle use by level of asthma attack severity.</b>                            | <b>90</b>  |
| <b>Table 27: Chest sounds by level of asthma attack severity.</b>                                    | <b>90</b>  |
| <b>Table 28: Posture by level of asthma attack severity.</b>                                         | <b>90</b>  |
| <b>Table 29: Behaviour by level of asthma attack severity.</b>                                       | <b>91</b>  |
| <b>Table 30: The ability to talk by level of asthma attack severity.</b>                             | <b>91</b>  |
| <b>Table 31: The ability to feed by level of asthma attack severity.</b>                             | <b>92</b>  |
| <b>Table 32: The ability to walk by level of asthma attack severity.</b>                             | <b>92</b>  |
| <b>Table 33: The ability to sleep by level of asthma attack severity.</b>                            | <b>92</b>  |
| <b>Table 34: Description of activity from each of the 3 rounds of the eDelphi study</b>              | <b>101</b> |

|                                                                                                                                                                                                             |            |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| <b>Table 35: Recruitment sources with numbers of potential participants the recruitment emails reached. ....</b>                                                                                            | <b>104</b> |
| <b>Table 36: Details of other sources of recruitment contacted and rationale for being unable to circulate the survey .....</b>                                                                             | <b>104</b> |
| <b>Table 37: Characteristics of participants according to clinical practice who completed all three rounds of the eDelphi study. ....</b>                                                                   | <b>109</b> |
| <b>Table 38: Characteristics of participants according to country, main discipline of clinical practice, scope of practice and expertise of asthma and NFA attacks who completed all three rounds. ....</b> | <b>110</b> |
| <b>Table 39: Results of round one of the eDelphi .....</b>                                                                                                                                                  | <b>122</b> |
| <b>Table 40: Results of round two edelphi.....</b>                                                                                                                                                          | <b>130</b> |
| <b>Table 41: Definition of near-fatal asthma stem.....</b>                                                                                                                                                  | <b>132</b> |
| <b>Table 42: Results of options provided for definition of near fatal asthma. ....</b>                                                                                                                      | <b>133</b> |
| <b>Table 43: A comparison of eDelphi studies considering participation, number of countries represented, number of rounds and % attrition rate.....</b>                                                     | <b>138</b> |
| <b>Table 44: An explanation of the four notions which help define qualitative research adapted from Aspers and Corte (2019).....</b>                                                                        | <b>145</b> |
| <b>Table 45: Ontological and epistemological assumptions of positivism, post-positivism, constructivism/interpretivism and critical theory. ....</b>                                                        | <b>150</b> |
| <b>Table 46: The fundamental components of a grounded theory study .....</b>                                                                                                                                | <b>153</b> |
| <b>Table 47: Number of invitations sent to potential participants from PIC.....</b>                                                                                                                         | <b>159</b> |
| <b>Table 48: An explanation of the transcription process used in this study. ....</b>                                                                                                                       | <b>163</b> |
| <b>Table 49: A comparison of key processes from different analytic approaches adapted from Rapley (2016). ....</b>                                                                                          | <b>164</b> |
| <b>Table 50: Characteristics of the young adults who participated in the NFA attack interviews in order of interview date. ....</b>                                                                         | <b>172</b> |

|                                                                                                                                                    |     |
|----------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| <b>Table 51: Characteristics of the parent(s) and their child who participated in the near fatal asthma interviews in order of interview date.</b> | 173 |
| <b>Table 52: Characteristics of the participants in the fatal asthma interviews.</b>                                                               | 196 |
| <b>Table 53: The five stages of the conscious competence model.</b>                                                                                | 226 |
| <b>Table 54 Key findings from the qualitative research with parents and young adults as outlined by constructs of the socio-ecological model.</b>  | 235 |

## **List of figures**

|                                                                                                                          |     |
|--------------------------------------------------------------------------------------------------------------------------|-----|
| <b>Figure 1: Diagnostic algorithm</b>                                                                                    | 9   |
| <b>Figure 2: Summary of management in children</b>                                                                       | 12  |
| <b>Figure 3: Management of acute asthma attack in children aged 5 years and above.</b>                                   | 18  |
| <b>Figure 4: Airway changes during an asthma attack</b>                                                                  | 23  |
| <b>Figure 5 Social Ecological Model Displaying the Multilevel Factors</b>                                                | 37  |
| <b>Figure 6: Adapted from Review Ready Reckoner - Assessment Tool (RRRsAT)</b>                                           | 41  |
| <b>Figure 7: Flow chart diagram of scoping review</b>                                                                    | 46  |
| <b>Figure 8: Positions of accessory muscles.</b>                                                                         | 66  |
| <b>Figure 9: The method used to undertake an international eDelphi study.</b>                                            | 102 |
| <b>Figure 10: Number of participants by country across each all 3 rounds of eDelphi</b>                                  | 116 |
| <b>Figure 11: Number of participants by continent across all 3 rounds of the eDelphi</b>                                 | 117 |
| <b>Figure 12: Distribution of participants according to self-ranked expertise in asthma management</b>                   | 118 |
| <b>Figure 13: Distribution of participants according to self-ranked expertise in managing near fatal asthma attacks.</b> | 118 |



|                                                                                                                                                                               |     |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| <b>Figure 14: Other names used by participants to describe a critical asthma attack</b>                                                                                       | 119 |
| <b>Figure 15: Peak Flow Values (% predicted)</b>                                                                                                                              | 123 |
| <b>Figure 16: Heart rate (bpm)</b>                                                                                                                                            | 124 |
| <b>Figure 17: Oxygen saturation (%)</b>                                                                                                                                       | 124 |
| <b>Figure 18: Respiratory rate (per minute)</b>                                                                                                                               | 125 |
| <b>Figure 19: Capillary refill (seconds)</b>                                                                                                                                  | 125 |
| <b>Figure 20: AVPU (Alert, Verbal, Pain, Unresponsive) values</b>                                                                                                             | 126 |
| <b>Figure 21: pH values</b>                                                                                                                                                   | 126 |
| <b>Figure 22: Pulsus Paradoxus (mmHg) values</b>                                                                                                                              | 127 |
| <b>Figure 23: PaO<sub>2</sub> (mmHg) values</b>                                                                                                                               | 127 |
| <b>Figure 24: PaCO<sub>2</sub> (mmHg) values</b>                                                                                                                              | 128 |
| <b>Figure 25: Lactate (mmol/L) values</b>                                                                                                                                     | 128 |
| <b>Figure 26: Highly and quite specialised experts preferred value for SpO<sub>2</sub></b>                                                                                    | 134 |
| <b>Figure 27: Highly and quite specialised experts preferred value for PaCO<sub>2</sub></b>                                                                                   | 134 |
| <b>Figure 28: The building blocks forming the research paradigm and how they interrelate</b>                                                                                  | 148 |
| <b>Figure 29: Themes identified of key time critical experiences highlighting potential opportunities to seek medical help</b>                                                | 175 |
| <b>Figure 30: The themes and subthemes identified of behaviours and circumstances that may place children and young people at risk of a near fatal or fatal asthma attack</b> | 181 |
| <b>Figure 31: Themes identified of key time critical experiences highlighting potential opportunities to seek medical help</b>                                                | 198 |

|                                                                                                                                                                                                 |     |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
| Figure 32: The themes and subthemes created of potentially modifiable behaviours and circumstances that may place children and young people at risk of a near fatal or fatal asthma attack..... | 203 |
| Figure 33: Child's asthma plan available from <a href="http://www.asthma.org.uk/advice/child/manage/action-plan">www.asthma.org.uk/advice/child/manage/action-plan</a> .....                    | 218 |
| Figure 34: Suggested SUDEP discussion pathway for a recently diagnosed patient with epilepsy.....                                                                                               | 223 |
| Figure 35 Socio-ecological model displaying the multilevel factors that could reduce Near fatal attacks and prevent asthma deaths in children and young people.....                             | 249 |

## List of boxes

|                                                                                                                   |     |
|-------------------------------------------------------------------------------------------------------------------|-----|
| Box 1: Common Asthma triggers .....                                                                               | 19  |
| Box 2: Search strategy used to identify studies from 4 databases.....                                             | 44  |
| Box 3: Search strategies for asthma attack guidelines from initial review in 2017 and updated search in 2019..... | 82  |
| Box 4: Asthma MeSH descriptor data .....                                                                          | 98  |
| Box 5: ICD-11 Scoring tool for Asthma Attacks .....                                                               | 98  |
| Box 6: An asthma attack in a young person with a positive outcome.....                                            | 231 |
| Box 7: An asthma attack in a young person with an adverse outcome.....                                            | 232 |

## List of Appendices

|                                                                                                                           |     |
|---------------------------------------------------------------------------------------------------------------------------|-----|
| Appendix 1: Ethical approval from Usher .....                                                                             | 281 |
| Appendix 2: Email invitation to potential participants .....                                                              | 282 |
| Appendix 3: Participant Information sheet for eDelphi.....                                                                | 283 |
| Appendix 4: Young adult perspective of a near fatal asthma attack, participant information sheet distributed by PIC. .... | 285 |

|                                                                                                                                    |            |
|------------------------------------------------------------------------------------------------------------------------------------|------------|
| <b>Appendix 5: Parent/ carer perspective of a near fatal asthma attack, participant information sheet distributed by PIC. ....</b> | <b>289</b> |
| <b>Appendix 6: Parent/ carer perspective of a fatal asthma attack, participant information sheet.....</b>                          | <b>293</b> |
| <b>Appendix 7: Consent form for young adult NFA study .....</b>                                                                    | <b>297</b> |
| <b>Appendix 8: Consent form for parent/ carer NFA study .....</b>                                                                  | <b>299</b> |
| <b>Appendix 9: Consent form for parent/ carer FA study .....</b>                                                                   | <b>301</b> |
| <b>Appendix 10: Topic guide for both NFA studies .....</b>                                                                         | <b>303</b> |
| <b>Appendix 11: Topic guides for FA study.....</b>                                                                                 | <b>305</b> |
| <b>Appendix 12: Letter of support from Leo Campbell to the Ethics Committee</b>                                                    | <b>306</b> |
| <b>Appendix 13: Ethical approval for qualitative interviews .....</b>                                                              | <b>307</b> |

## **Contributions to science**

### **Oral presentations**

Oral presentation: McMurray A., Cunningham S., Fleming L. Defining Near-fatal asthma – an international eDelphi Study. Presented at AUKCAR Annual Scientific Meeting. (London, March 2019)

Oral presentation: McMurray A., Cunningham S., Fleming L. Defining Near-fatal asthma – an international eDelphi Study. Presented King's John Price Paediatric Respiratory Conference. (London, April 2019)

Oral presentation: McMurray A. Asthma deaths, near-fatal asthma and spotting the at risk child. South East Scotland Paediatric Asthma Meeting. (Edinburgh, 2019)

Oral presentation: McMurray A. Parent and young person's perspective of near-fatal asthma. Presented King's John Price Paediatric Respiratory Conference. (Online, May 2021)

Oral presentation: McMurray A. Giving a voice to families and young people. Prevention of asthma deaths in childhood, The Royal Society of Medicine. (Online, September, 2021)

### **Poster presentations**

Poster presentation: McMurray A., Cunningham S., Fleming L. Defining acute asthma severity – how do worldwide guidelines compare? Presented at AUKCAR Annual Scientific Meeting. (Bristol, January 2018)

Poster presentation: McMurray A., Cunningham S., Fleming L. Defining acute asthma severity – how do worldwide guidelines compare? Displayed at The European Respiratory Society Conference. (Paris, 2018)

Poster presentation: McMurray A., Cunningham S., Fleming L. Defining Near-fatal asthma – an international eDelphi Study. Presented at The European Respiratory Society Conference. (Madrid, 2019)

## **Abbreviations**

|        |                                        |
|--------|----------------------------------------|
| A      | Adult                                  |
| AAA    | Acute Asphyxial Asthma                 |
| ABG    | Arterial Blood Gas                     |
| ASM    | Annual Scientific Meeting              |
| AUK    | Asthma UK                              |
| AVPU   | Alert, Verbal, Pain, Unresponsive      |
| AUKCAR | Asthma UK Centre for Applied Research  |
| BP     | Blood Pressure                         |
| BTS    | British Thoracic Society               |
| C      | Circa                                  |
| CAM    | Complementary and Alternative Medicine |
| CAS    | Critical Asthma Syndrome               |
| CBG    | Capillary Blood Gas                    |
| CC     | Critical Care                          |
| CR     | Case Review                            |
| CS     | Cohort study                           |
| CYP    | Children and Young People              |
| DGH    | District General Hospital              |
| ECMO   | Extracorporeal Membrane Oxygenation    |
| ED     | Emergency Department                   |
| EO     | Expert Opinion                         |
| EU     | European Union                         |
| FeNO   | Fractional Exhaled Nitric Oxide        |
| GCS    | Glasgow Coma Scale                     |

|       |                                                     |
|-------|-----------------------------------------------------|
| GINA  | Global Initiative for Asthma                        |
| GP    | General Practitioner                                |
| GT    | Grounded theory                                     |
| HCP   | Health Care Professional                            |
| HR    | Heart Rate                                          |
| ICD   | International Classification of Diseases            |
| ICL   | Imperial College London                             |
| ICS   | Inhaled Corticosteroids                             |
| ICU   | Intensive Care Unit                                 |
| IRAS  | Integrated Research Application System              |
| IPCRG | International Primary Care Research Group           |
| IV    | Intravenous                                         |
| kPa   | Kilopascals                                         |
| L     | Litre                                               |
| LABA  | Long-Acting Beta Agonist                            |
| LTA   | Life threatening                                    |
| LTRA  | Leukotriene Receptor Antagonist                     |
| M     | Mixed                                               |
| MART  | Maintenance and Reliever Therapy                    |
| MeSH  | Medical Subject Headings                            |
| MHRA  | Medicines and Healthcare Products Regulatory Agency |
| mmHg  | Millimetre of mercury                               |
| mmol  | Millimole                                           |
| NFA   | Near-Fatal Asthma                                   |
| NFAYP | Near-Fatal Asthma Young Adult                       |

|                   |                                                   |
|-------------------|---------------------------------------------------|
| NHS               | National Health Service                           |
| NIV               | Non-Invasive Ventilation                          |
| NICE              | National Institute for Health and Care Excellence |
| NRAD              | National Review of Asthma Deaths                  |
| O <sub>2</sub>    | Oxygen                                            |
| P                 | Paediatric                                        |
| PaCO <sub>2</sub> | Partial Pressure of Carbon Dioxide                |
| PaO <sub>2</sub>  | Partial Pressure of Oxygen                        |
| PC                | Primary Care                                      |
| PEFR              | Peak Expiratory Flow Rate                         |
| PIC               | Participant Identification Centre                 |
| PhD               | Doctor of Philosophy                              |
| PICANet           | Paediatric Intensive Care Audit Network           |
| PP                | Pulsus Paradoxus                                  |
| PPI               | Patient and Public Involvement                    |
| PRAM              | Pediatric Respiratory Assessment Measure          |
| PSA               | Problematic Severe Asthma                         |
| PTS               | Post-Traumatic Stress                             |
| R                 | Respiratory                                       |
| REC               | Research Ethics Committee                         |
| RR                | Respiratory Rate                                  |
| SA                | Status Asthmaticus                                |
| SABA              | Short-Acting Beta Agonist                         |
| SC                | Secondary Care                                    |
| SLTA              | Severe Life-Threatening Asthma                    |

|                  |                                             |
|------------------|---------------------------------------------|
| SIGN             | Scottish Intercollegiate Guidelines Network |
| SpO <sub>2</sub> | Peripheral Capillary Oxygen Saturation (%)  |
| SUDEP            | Sudden Unexplained Death in Epilepsy        |
| UK               | United Kingdom                              |
| USA              | United States of America                    |
| UoE              | University of Edinburgh                     |
| VBG              | Venous Blood Gas                            |

|    |                  |
|----|------------------|
| DC | Debbie Cavers    |
| LF | Louise Fleming   |
| MD | Marshall Dozier  |
| MK | Marilyn Kendall  |
| SC | Steve Cunningham |



# **1 Chapter one – Overview of thesis**

## **1.1 Overview of this PhD**

Asthma is one of the most common long-term conditions in children. Despite advances in the understanding of the mechanisms of asthma, asthma attacks and asthma-related deaths remain problematic. This PhD programme of work was split into two components. The first component focused on defining near-fatal asthma (NFA). The second component was a qualitative study to explore the experiences of parents and young adults affected by NFA and parents affected by fatal attacks.

## **1.2 Asthma UK Centre for Applied Research**

The Asthma UK Centre for Applied Research (AUKCAR) is a virtual Centre combining leading asthma researchers from universities in the UK. Within the centre there are two key themes of research:

- Theme one – preventing asthma attacks.
- Theme two – optimising asthma management to reduce hospitalisation, readmissions and deaths.

The qualitative research approach of my study and its methods fit within the ethos of the Centre, which is patient and parent/ carer focused.

## **1.3 Research environment and available expertise**

PhD studentships within the AUKCAR are required to have supervisory teams comprised of supervisors from more than one university. My supervisors were affiliated to the University of Edinburgh (UoE) and Imperial College London (ICL):

- Professor Steve Cunningham (SC), Principal Supervisor - UoE
- Dr Marilyn Kendall (MK) - UoE
- Dr Debbie Cavers (DC) - UoE
- Dr Louise Fleming (LF) - ICL

In addition to their academic roles, two of my supervisors also hold clinical positions within tertiary care respiratory departments (SC and LF). I also had a clinical working relationship with my principal supervisor as a specialist nurse.

Steve Cunningham is a paediatric respiratory paediatrician with over 30 years experience of supporting children with asthma, both clinically and through research. His clinical skills as an acute admitting paediatrician provided experience of severe acute wheeze, including critical care management and asthma death. Experience of the chronic management of asthma has been gained over this period within asthma review clinics and by discussion with colleagues of complex cases and associated learning. He now runs a critical care asthma clinic dedicated to the review of children and families who have experienced a critical care admission with acute asthma. SC was a member of the UK SIGN/BTS guideline group for over 10 years and also clinician contributor to the NRAD review. He has extensive research experience both academically and commercially, with studies in relation to asthma within this portfolio both from a mechanistic and management perspective. SC has been a member of MHRA committees assessing the safety and efficacy/effectiveness of asthma medicines for over 20 years.

Marilyn Kendall is an experienced qualitative researcher who worked within the Primary Palliative Care Group at the Usher Institute at the University of Edinburgh for 20 years until her retirement in 2019. She had a wealth of experience conducting qualitative research in end of life care, with meaningful involvement of patients and the public in the research process at the heart of every project. She set up and ran patient and public involvement groups, including a long-running group in Dumfries who have offered their insights and perspectives across many research projects over the years.

Debbie Cavers is a health services researcher and qualitative methodologist with 20 years' experience. DC has worked primarily in the field of cancer care, exploring

patient, carer and professional perspectives to understand lived experiences and inform the development of services and interventions to improve person-centred care. More recently, DC has begun to explore the intersection of chronic conditions and the impact of this on experiences and outcomes.

Louise Fleming is a paediatric respiratory paediatrician with over 20 years of experience managing children with asthma, both acutely and for long term management. She has worked in a variety of health settings including in primary and secondary care in West Africa where she ran asthma clinics in a resource poor setting. Over the past 10 years she has led a severe asthma service and receives tertiary and quaternary referrals of complex cases. She works within a multi-disciplinary team which takes a systematic approach to the management of difficult to treat asthma in order to determine and remediate factors contributing to poor control. A large proportion of these children have had a critical care admission and most have had at least four severe attacks in the year preceding referral. Over this period her academic work has focussed almost exclusively on asthma, including single centre observational studies, intervention studies, industry led clinical trials, and large international collaborations. She was previously a member of the UK BTS/SIGN guideline group and for the past 4 years has been a member of the GINA Science Committee.

The AUKCAR provides an infrastructure which is available to support PhD students that included a postgraduate training coordinator, training events with other PhD students and opportunities to network at national and international conferences.

#### **1.4 Patient Public Involvement (PPI)**

Involving people affected by asthma in research is an important part of AUKCAR work.

There has been ongoing PPI with my study which have included:

- involvement with study design

- reading of participant information leaflets
- reading of the lay person summary for participants, ethics application and thesis abstract
- future assistance will be required to disseminate results of the study

## **1.5 Note on terminology**

One of the aims of this PhD thesis was to gain an international consensus agreement for the name of the asthma attack at the most severe end of the spectrum. For the purposes of this thesis the name 'critical asthma attack' will be used in the scoping review (chapter three) and the eDelphi chapter (chapter five) prior to consensus being obtained. The name 'near-fatal asthma' will be used in all other chapters as this was the preferred name of the eDelphi participants and is used within asthma guidelines.

## **1.6 Outline of the thesis chapters**

The outline of the thesis is as follows:

**Chapter One** provides an overview of this thesis with a brief summary of each chapter.

**Chapter Two** provides an introduction to asthma, asthma attacks, near-fatal asthma and findings from asthma death enquires. The aims of the thesis are outlined.

**Chapter Three** is a scoping review of a critical asthma attack. This type of attack is considered as a separate entity to life threatening asthma. The scoping review aimed to identify the names and definitions used to describe a critical asthma attack, clinical features and objective measurements. Patient/ parent/carer experience of the event in a child (over 5 years), adolescent and young adult (up to age 24 years) population were also part of the review.

**Chapter Four** is a review of global asthma guidelines in relation to the inclusion of NFA as a recognised attack. It also explores the clinical features and objective measurements according to attack severity.

**Chapter Five** is an international eDelphi study which aimed to agree a name and definition of a critical asthma attack.

**Chapter Six** details the chosen design and methods of the qualitative study, with justification for choosing this approach.

**Chapter Seven** reports the findings of the interviews with parents and young adults who had experienced NFA.

**Chapter Eight** reports the findings of the interviews with parents of children who had died due to an asthma attack.

**Chapter Nine** discusses the themes created from the findings of both chapter seven and eight and places them in context with the current literature.

**Chapter Ten** provides a summary of the thesis and recommendations for people with asthma, professionals and clinical services, for policy makers, and for future research.

## **2 Chapter two: Introduction**

### **2.1 Overview of asthma**

Asthma is a “heterogeneous (diverse or variable) disease, usually characterised by chronic airway inflammation. It is defined by the history of respiratory symptoms such as wheeze, shortness of breath, chest tightness and cough that vary over time and in intensity, together with variable expiratory airflow limitation” (Global Initiative for Asthma, 2021) .

Asthma is one of the most common long-term conditions, affecting 1 in 11 children and 1 in 12 adults within the United Kingdom (UK) (Asthma UK, 2021a). Typically there are more boys affected in childhood, and girls in adolescence and adulthood. The rationale for this gender divide is not clearly understood, although there is evidence that hormonal changes may be a contributory factor (Postma, 2007, McCleary et al., 2018). There are an estimated 5.4 million people currently living with the condition in the UK, including one million children, (Asthma UK, 2021a). Globally, this figure is 334 million (including both adult and children). This statistic may, however, be inaccurate, as diagnosis varies between and within countries and may result in over or under-diagnosis (Asher and Pearce, 2014, Yang et al., 2017, Looijmans-Van den Akker et al., 2016). Asthma attacks are common, with someone experiencing an attack every ten seconds in the UK (Asthma UK, 2021a). Asthma deaths, whilst uncommon, were estimated to be responsible for 417, 918 fatalities globally in 2016 (World Health Organization, 2020). Near-fatal asthma (NFA) attacks represent the most severe end of the spectrum of asthma attacks. Their incidence is unknown and this may be attributed to the current lack of consensus definition for near-fatal asthma and the differing terminology used within clinical practice (see chapter 5). Risk factors (Table 1) have been identified for both fatal and NFA attacks in adults and children and are contained within the British Guideline on the

Management of Asthma (British Thoracic Society (BTS)/ Scottish Intercollegiate Guidelines Network (SIGN), 2019).

**TABLE 1: PATIENTS AT RISK OF DEVELOPING NEAR-FATAL OR FATAL ASTHMA**

From The British Guideline on the Management of Asthma (BTS/SIGN, 2019).

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| A combination of severe asthma recognised by one or more of:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| <ul style="list-style-type: none"> <li>• previous near-fatal asthma, e.g. previous ventilation or respiratory acidosis</li> <li>• previous admission for asthma, especially if in the last year</li> <li>• requiring three or more classes of asthma medication</li> <li>• heavy use of <math>\beta</math>2 agonist</li> <li>• repeated attendances at ED for asthma care, especially if in the last year</li> </ul>                                                                                                                                                                                                                                               |
| AND adverse behavioural or psychosocial features recognised by one or more of:                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• non-adherence with treatment or monitoring</li> <li>• failure to attend appointments</li> <li>• fewer GP contacts</li> <li>• frequent home visits</li> <li>• self-discharge from hospital</li> <li>• psychosis, depression, other psychiatric illness or deliberate self-harm</li> <li>• current or recent major tranquilliser use</li> <li>• denial</li> <li>• alcohol or drug abuse</li> <li>• obesity</li> <li>• learning difficulties</li> <li>• employment problems</li> <li>• income problems</li> <li>• social isolation</li> <li>• childhood abuse</li> <li>• severe domestic, marital or legal stress</li> </ul> |

## 2.2 Diagnosis of asthma

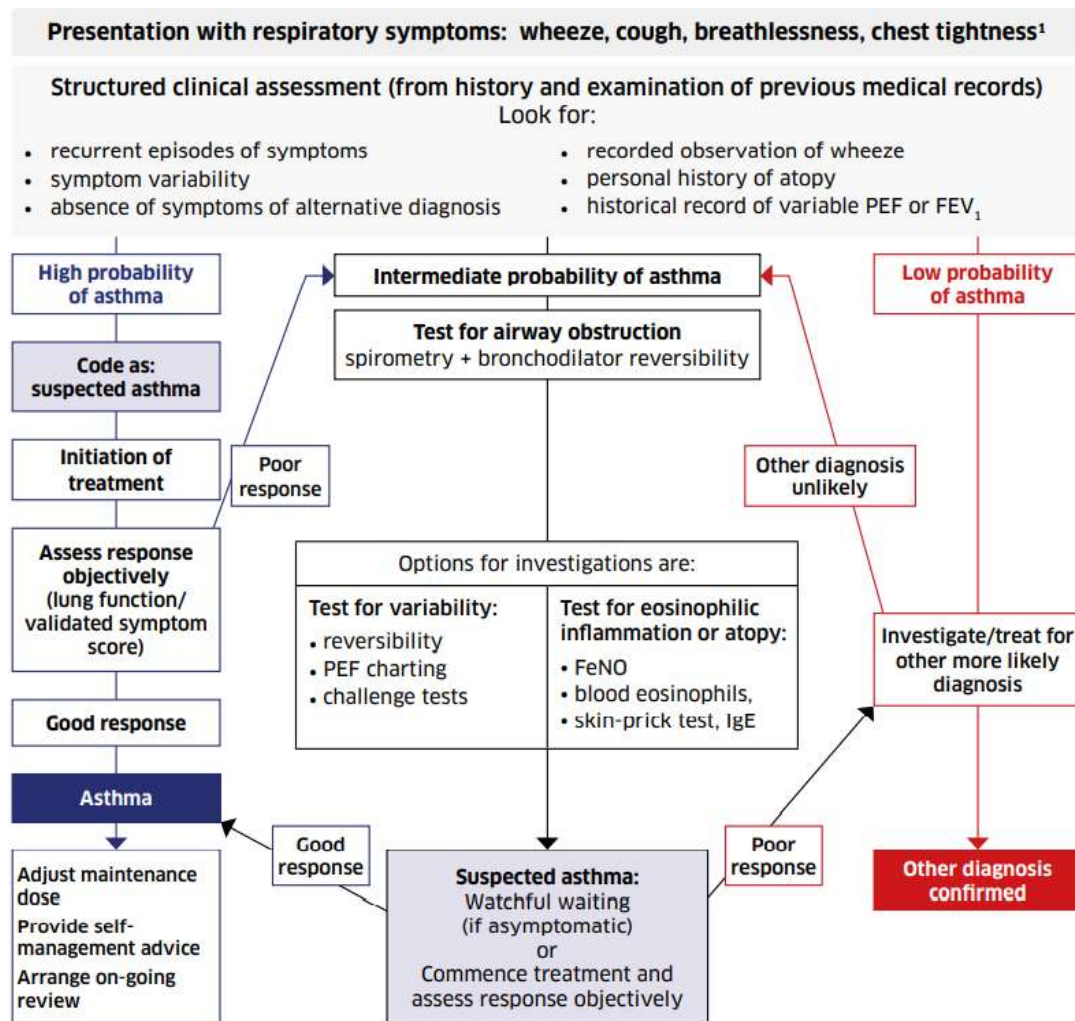
Asthma is a clinical diagnosis; there is currently no single diagnostic test available to confirm a diagnosis of asthma (BTS/SIGN, 2019). There are two current asthma guidelines available within the UK which focus on asthma diagnosis and management of children and adults: the British Guideline on the Management of Asthma and Asthma: Diagnosis, Monitoring and Chronic Asthma Management (BTS/SIGN, 2019, National Institute for Health and Care Excellence (NICE), 2021). Both guidelines recommend an assessment of symptoms and clinical examination, supported by

objective tests such as peak flow monitoring or spirometry that can demonstrate variable airflow obstruction (Figure 1). The inclusion of a test to measure airway inflammation, Fractional Exhaled Nitric Oxide (FeNO), has been recommended within the diagnostic pathways of the guidelines to enable a more informed diagnosis. There is a variation between the two asthma guidelines about the importance of this test. NICE place FeNO prominently within their guideline and BTS/SIGN list it as 'potentially useful' (White et al., 2018). Recently, Gaillard and Moeller published a new European guideline for the diagnosis of asthma in children aged five to 16 years (Gaillard and Moeller, 2021). Their key recommendation is to perform a series of diagnostic tests which include spirometry with reversibility and a FeNO test. Although diagnostic testing can be supportive of a diagnosis, ultimately the diagnosis is clinical. For the purposes of this thesis I will refer to the BTS/SIGN guideline, which is widely used by clinicians in the UK.



**FIGURE 1: DIAGNOSTIC ALGORITHM**

Used with permission from Scottish Intercollegiate Guidelines Network (2019)



## 2.3 Asthma phenotypes

Asthma, like arthritis or epilepsy, is an umbrella term used to describe many different types of asthma. Relating to adults and children, Wenzel described five phenotypes (a set of observable characteristics): early-onset allergic, late-onset eosinophilic, exercise-induced, obesity-related and neutrophilic (Wenzel, 2012). Ross et al., adds to this list by including phenotypes identified using secondary data analysis from clinical studies and these include allergic-related, obesity-related, early-onset, late-onset, viral-induced, symptom-related, smoking-related, exercise-induced, and aspirin-related asthma (Ross et al., 2018). Within paediatric practice phenotypic

classifications vary globally and often cause confusion based on how the word phenotype has been defined (Gupta et al., 2018). It is used to describe:

- any observable trait (morphological, biochemical, physiological, behavioural)
- clinical grouping for wheeze/asthma (pre-school wheeze, difficult/severe asthma)
- specific disease entities (atopic asthma, viral induced wheeze)

(Henderson et al., 2009)

Gupta et al., argue that observable traits are the most useful and these traits are presented in Table 2.

**TABLE 2: CLASSIFICATION OF ASTHMA PHENOTYPES IN CHILDREN**  
(Adapted from Gupta et al., 2018)

|                                                                                           |
|-------------------------------------------------------------------------------------------|
| <b>Symptom based</b>                                                                      |
| • Age at onset                                                                            |
| • Natural history                                                                         |
| • Severity                                                                                |
| <b>Trigger based</b>                                                                      |
| • Allergic vs. non-allergic                                                               |
| • Exercise induced                                                                        |
| • Viral triggered vs. multi triggered.                                                    |
| <b>Response to treatment</b>                                                              |
| • Corticosteroid responsive                                                               |
| <b>Inflammatory features</b> (based on biopsy, induced sputum and bronchoalveolar lavage) |
| • Eosinophilic                                                                            |
| • Neutrophilic                                                                            |
| <b>Non-invasive markers</b>                                                               |
| • Exhaled nitric oxide                                                                    |
| <b>Pulmonary function tests</b>                                                           |
| • Fixed vs. bronchodilator-reversible airway obstruction                                  |
| • Bronchial responsiveness to exercise, cold air, chemical challenge.                     |

The Lancet commission encourages clinicians to identify the pathophysiology and treatable aspects in an individual child and to tailor treatment accordingly, so-called “treatable traits” (Pavord et al., 2018). Although not routinely practiced for children with mild to moderate asthma this approach has been used in the management of children with severe problematic asthma. If a child presents with asthma which is

apparently resistant to therapy with high-dose inhaled corticosteroids (ICS) and other controllers, this is defined as problematic severe asthma (Bush et al., 2017). The authors present an approach to management, which aims to identify the pathophysiology, address modifiable factors (adherence, allergen exposure), carry out investigations and devise an individualised treatment plan that may include a biological treatment.

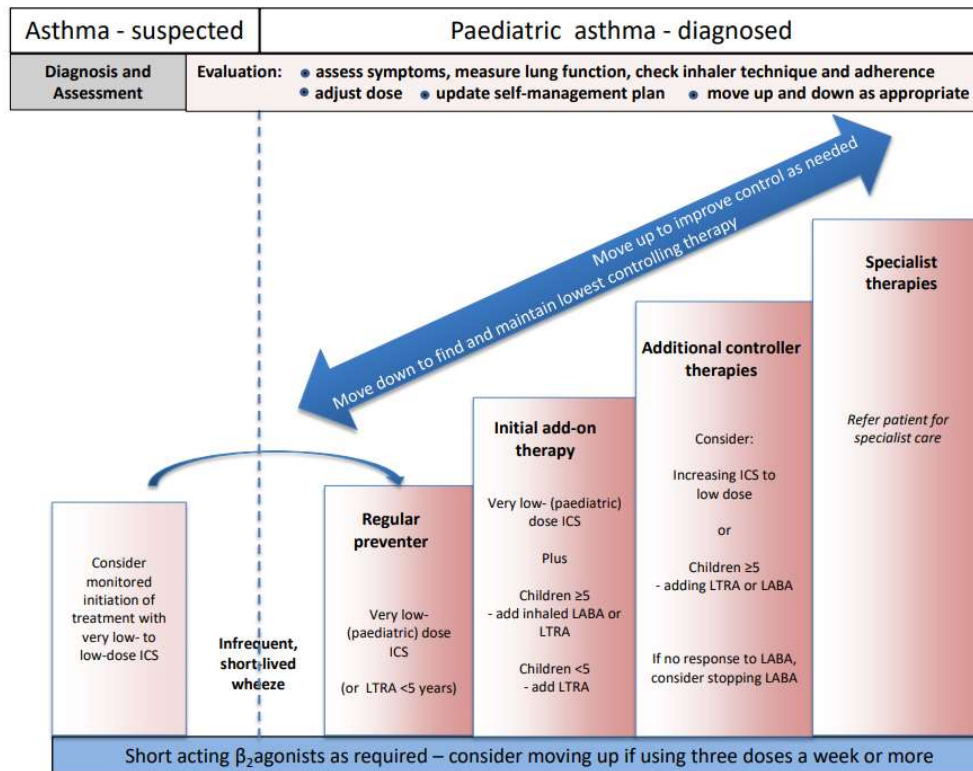
## **2.4 Asthma medication**

In examining both the causes and possible preventative measures of NFA attack incidence, it is important to evaluate the available asthma medications, their efficacy and how mismanagement may contribute to NFA attacks and asthma deaths. This section will provide a brief overview of the medications used to control asthma and also the medications used to manage an attack.

Patients with good asthma control should be symptom-free day and night, be able to take part in sports and activities, have minimal reliever inhaler use and not experience any asthma attacks. Asthma medication should be maintained at the lowest possible dose to prevent side effects whilst achieving good asthma control (BTS/SIGN, 2019). Asthma is managed, for the majority of patients, using ICS as preventer treatment and short acting beta agonists (SABA) for acute relief of symptoms. Asthma medications are managed according to a stepwise progression with increasing doses of ICS and addition of other preventer therapies such as long-acting beta agonists (LABA) or leukotriene receptor antagonists (LTRA) if control is poor. Guidance on medications and doses are available within the British Guideline on the Management of Asthma and an approach to management are presented in Figure 2 (BTS/SIGN, 2019).

**FIGURE 2: SUMMARY OF MANAGEMENT IN CHILDREN**

Used with permission from Scottish Intercollegiate Guidelines Network (2019)



#### 2.4.1 SABA/ Relievers

SABA or  $\beta_2$ -adrenoceptor agonist (salbutamol/terbutaline) relieve acute asthma symptoms. As either a dry powder or aerosol preparation they are blue in colour and are often referred to by patients as their 'blue inhaler'. At therapeutic doses they act on the  $\beta_2$ -adrenoceptors of bronchial muscle, providing short acting (4-6 hour) bronchodilation, with a fast onset of action (within 5 minutes) in reversible airways obstruction (Ullmann et al., 2015). For over 60 years, standard asthma treatment has included SABA, including as monotherapy in patients with mild asthma symptoms (Kaplan et al., 2020). It does not address the underlying inflammatory process (see section 2.6) and does not protect the patient from attacks. Using SABA alone, or excessively, are recognised risk factors for asthma attacks or asthma deaths (Levy et al., 2018, Suissa et al., 1994, Nwaru et al., 2020a). Clinicians need to have processes

in place to monitor SABA prescribing, such as placing alerts on primary care systems (McKibben et al., 2018). These systems however need to be supported with patient review and education for both clinicians, patients and their families (Cheetham et al., 2020).

#### **2.4.2 Inhaled corticosteroids (ICS)**

Inhaled corticosteroids are the current gold standard in asthma management (BTS/SIGN, 2019). ICS are of greater benefit for those with eosinophilic inflammation (commonly associated with atopic disease) versus non-eosinophilic (neutrophilic) inflammation. In adults, non-eosinophilic asthma is characterised by the absence of airway eosinophilia and normal sub epithelial layer thickness. It represents a pathologically distinct disease phenotype, which has demonstrated a poor short-term response to treatment with inhaled corticosteroids (Berry et al., 2007). ICS control the swelling and inflammation in the airways, reducing airway hyper-responsiveness and reducing the risk of severe attacks. The protective effect builds up over a period of approximately 48 hours, however this effect will wear off if not taken on a daily basis. ICS need to be taken every day (usually morning and evening) even when the child is feeling well (Asthma UK, 2021b). These inhalers are usually brown (e.g. Clenil Modulite) or orange (e.g. Flixotide) in colour. As new products are emerging, manufacturers are choosing to deviate from the original colour scheme, e.g. Soprabec 100mcg in a grey canister. The divergence of product colour for commercial purposes, could cause confusion amongst healthcare providers, care providers and patients, who are familiar with referring to the ICS as the brown inhaler. Some children and young people (CYP) with mild asthma are not currently treated with ICS in the UK. This may change in the future as the Global Initiative for Asthma (GINA, 2021) have recently updated their strategy for children  $\geq 12$  years with a recommendation that a low dose combination ICS-formoterol (a fast acting LABA) should be the preferred reliever, excluding the use of SABA alone (Santamaria et al.,

2021). BTS/SIGN currently recommend that if a child is using their SABA inhaler more than 3 times a week, they should have a review with their GP or practice nurse to discuss initiation of ICS treatment (BTS/SIGN, 2019).

### 2.4.3 Combination inhalers

A combination inhaler is a medication composed of both ICS and LABA. A LABA is similar to a SABA however they have a longer duration of action (typically 12 hours for LABA compared with up to 4 hours for SABA). Although available as a separate inhaler, a LABA should not be used as monotherapy for asthma, but only in fixed-dose combination devices also containing an ICS (Tesse et al., 2018). LABA only treatment can provide relief of symptoms through bronchodilation, but leave inflammation untreated, thus increasing the risk of an attack and asthma-related death (Castle et al., 1993, Nelson et al., 2006, Cates et al., 2012). Combination inhalers have benefits that include improving adherence and keeping prescribing costs down (using one inhaler instead of two) (Rajesh et al., 2020). Some combination inhalers can also be used as a monotherapy by implementing a Maintenance And Reliever Therapy (MART) approach which is slowly being adopted in some paediatric centres within the UK (Jorup et al., 2018, Reddel et al., 2019). The MART approach uses ICS-formoterol as both the regular preventative treatment and the reliever treatment as required. Limits in dosing are set by the clinician and in consultation with the patient and family. There are currently four combination inhalers available for children and young people (Table 3), although only Symbicort (budesonide-formoterol) is licensed for MART for children  $\geq 12$  years.

**TABLE 3: COMBINATION INHALERS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE**

Available from [www.bnf.nice.org.uk](http://www.bnf.nice.org.uk) (2021)

| Combination inhaler                    | Licence            |
|----------------------------------------|--------------------|
| fluticasone and salmeterol - Seretide  | 4 years and above  |
| budesonide and formoterol - Symbicort  | 6 years and above  |
| fluticasone and formoterol - Flutiform | 5 years and above  |
| fluticasone and vilanterol - Relvar    | 12 years and above |

#### **2.4.4 Leukotriene receptor antagonists (LTRA)**

LTRA block the release of leukotrienes, which are a contributing cause of airway inflammation (Barbosa et al., 2016). They are effective in approximately one third of children with asthma, based on their personal inflammatory profile and so are often prescribed on a trial basis initially (Bush, 2015). LTRA appear most effective if asthma symptoms are triggered by exercise or allergies (Wermuth et al., 2021). Unlike the majority of preventative asthma treatments, LTRA are administered orally and are usually well-tolerated with relatively few side effects for the majority of patients (Barbosa et al., 2016). The Medicines and Healthcare products Regulatory Agency (MHRA) however released a safety statement in 2019 advising of the potential risk of neuropsychiatric reactions (MHRA, 2019). This safety alert should ensure prescribers counsel parents and patients on the potential of a reaction and consider the benefits and risks of continuing treatment if they occur. LTRA includes montelukast (generic) and Singular (trade name).

#### **2.4.5 Other therapies**

While the majority of children and young people with asthma can be adequately managed following conventional guidelines, a minority have problematic severe asthma (PSA) which will require additional add-on treatment, some of which have very limited efficacy data in children (Pike et al., 2018). Table 4 presents a summary of the current treatments available which are prescribed after the child or young person has been assessed using a pathway (Bush et al., 2017).

**TABLE 4: MEDICATIONS USED FOR PROBLEMATIC SEVERE ASTHMA**

Adapted from Pike et al. (2018).

| Medications                                    |
|------------------------------------------------|
| Monoclonal antibodies (all given by injection) |
| • Omalizumab – anti-IgE                        |
| • Mepolizumab – anti-IL-5                      |
| • Dupilumab – anti-IL4 and IL-13               |
| Oral medications                               |
| • Oral bronchodilator e.g. Theophylline        |
| • Macrolide antibiotic e.g. Azithromycin       |
| • Immunosuppressant e.g. Ciclosporin           |
| Inhaled therapy                                |
| • Tiotropium                                   |

#### 2.4.6 Medications used for acute asthma attacks

Asthma attacks are treated with medications which aim to reduce airway inflammation and relieve bronchospasm. Figure 3 presents how an acute asthma attack is managed with medication and decision-making according to attack severity (BTS/SIGN, 2019).

Corticosteroids are used to treat airway inflammation. There are three corticosteroids currently used in the UK to treat acute wheeze:

- Prednisolone - given orally, once daily for a three to five day course.
- Dexamethasone - given orally, once daily as either a single dose or two day course.
- Hydrocortisone - given intravenously (IV) every 6 hours if unable to tolerate orally or if attack is severe/Life Threatening / NFA (British National Formulary for Children, 2021).

The current asthma guideline in the UK recommends the use of prednisolone for an asthma attack however acknowledges further studies are required to explore the benefits of single dose of dexamethasone (BTS/SIGN, 2019, Normansell et al., 2016). These benefits may include cost effectiveness and improved adherence with the completion of a course of treatment. There is current evidence to support the use of



dexamethasone in the treatment of asthma attacks in children so this may be considered in future UK guideline updates (Keeney et al., 2014).

There are four medications used to treat bronchospasm in the UK guideline for acute asthma attacks: SABA, ipratropium bromide, magnesium sulphate and aminophylline. These can be administered by inhaler and spacer, nebuliser or intravenously (IV) (Powell, 2016). Table 5 details the route of administration of bronchodilators used in an asthma attack.

**TABLE 5: BRONCHODILATORS AND THEIR ROUTE OF ADMINISTRATION**  
From BTS/SIGN (2019)

| Bronchodilator      | Route of administration                       |
|---------------------|-----------------------------------------------|
| SABA                | Meter dose inhaler via spacer, nebulised, IV. |
| Ipratropium bromide | Nebulised in conjunction with salbutamol      |
| Magnesium sulphate  | IV bolus or nebulised                         |
| Aminophylline       | IV                                            |

Ipratropium bromide is an anticholinergic bronchodilator that has a slower onset of action in comparison with a SABA and is recommended for use in a combined nebuliser with salbutamol (Powell and Cranswick, 2015, Rodrigo and Castro-Rodriguez, 2005). Magnesium sulphate has also been shown to provide benefit delivered via a nebuliser in children with severe asthma (Knightly et al., 2017, Powell et al., 2013). Aminophylline or salbutamol are used IV, however there is no current evidence supporting the use of one in preference to the other, with a recommendation that the choice should take into account factors such as ease of prescription, preparation and administration (Neame et al., 2005, Travers et al., 2012).

**FIGURE 3: MANAGEMENT OF ACUTE ASTHMA ATTACK IN CHILDREN AGED 5 YEARS AND ABOVE.**  
From Annex 8, British Guideline on the Management of Asthma (BTS/SIGN, 2019)

| Age >5 years                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ASSESS AND RECORD ASTHMA SEVERITY                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Moderate asthma</b> <ul style="list-style-type: none"> <li>• SpO<sub>2</sub> ≥92%</li> <li>• PEF &gt;50% best or predicted</li> <li>• No clinical features of severe asthma</li> </ul> <b>NB: If a patient has signs and symptoms across categories, always treat according to their most severe features</b>                                                                                                                                                                                                                                                                                                                                                                                     | <b>Acute severe asthma</b> <ul style="list-style-type: none"> <li>• SpO<sub>2</sub> &lt;92%</li> <li>• PEF 33–50% best or predicted</li> <li>• Heart rate &gt;125/min</li> <li>• Respiratory rate &gt;30/min</li> <li>• Use of accessory neck muscles</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | <b>Life-threatening asthma</b> <p>SpO<sub>2</sub> &lt;92% plus any of:</p> <ul style="list-style-type: none"> <li>• PEF &lt;33% best or predicted</li> <li>• Silent chest</li> <li>• Poor respiratory effort</li> <li>• Confusion</li> <li>• Cyanosis</li> </ul>                                                                                                                                                                                                                                                                                                                    |
| First-line treatments                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Oxygen via face mask/nasal prongs to achieve SpO <sub>2</sub> 94–98%                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <ul style="list-style-type: none"> <li>• β<sub>2</sub> bronchodilator: <ul style="list-style-type: none"> <li>- via spacer*</li> </ul> </li> <li>• Oral prednisolone 30–40 mg</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | <ul style="list-style-type: none"> <li>• β<sub>2</sub> bronchodilator <ul style="list-style-type: none"> <li>- via nebuliser (preferably oxygen-driven), salbutamol 5 mg</li> <li>- or, if nebuliser not available, via spacer*</li> </ul> </li> <li>• Oral prednisolone 30–40 mg or IV hydrocortisone 4 mg/kg if vomiting</li> <li>• Repeat β<sub>2</sub> bronchodilator up to every 20–30 minutes according to response</li> <li>• <b>If poor response</b> add 0.25 mg nebulised ipratropium bromide to every nebulised β<sub>2</sub> bronchodilator every 20 minutes for 1–2 hours</li> </ul>                                                                                                                                                                                                                                                                         | <ul style="list-style-type: none"> <li>• β<sub>2</sub> bronchodilator with ipratropium: <ul style="list-style-type: none"> <li>- via nebuliser (preferably oxygen-driven), salbutamol 5 mg and ipratropium 0.25 mg</li> </ul> </li> <li>• Repeat bronchodilators every 20–30 minutes</li> <li>• Oral prednisolone 30–40 mg or IV hydrocortisone 4mg/kg if vomiting</li> <li>• Consider adding 150 mg magnesium sulphate to each β<sub>2</sub> bronchodilator/ipratropium nebuliser in first hour</li> </ul> <p><b>Discuss with senior clinician, PICU team or paediatrician</b></p> |
| Reassess within 1 hour                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| ASSESS RESPONSE TO TREATMENT                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Record respiratory rate, heart rate, oxygen saturation and PEF/FEV every 1–4 hours                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Second-line treatments                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| <b>RESPONDING</b> <ul style="list-style-type: none"> <li>• Continue bronchodilators 1–4 hours as necessary</li> <li>• Discharge when stable on 4-hourly treatment</li> <li>• Continue prednisolone 30–40 mg daily until recovery (minimum 3–5 days)</li> </ul> <b>At discharge</b> <ul style="list-style-type: none"> <li>• Ensure stable on 4-hourly inhaled treatment</li> <li>• Review the need for regular treatment and the use of inhaled steroids</li> <li>• Review inhaler technique</li> <li>• Provide a written asthma action plan for treating future attacks</li> <li>• Arrange GP follow up within 48 hours</li> <li>• Arrange hospital asthma clinic follow up in 4–6 weeks</li> </ul> | <b>NOT RESPONDING</b> <ul style="list-style-type: none"> <li>• Continue 20–30 minute nebulisers</li> <li>• Consider chest X-ray and blood gases</li> <li>• Discuss with senior clinician, paediatrician or PICU</li> <li>• Consider admission to HDU/PICU</li> </ul> <p>Consider risks and benefits of:</p> <ul style="list-style-type: none"> <li>• <b>Bolus IV infusion of magnesium sulphate</b> 40 mg/kg (max 2 g) over 20 minutes</li> <li>• <b>Bolus IV salbutamol</b> 15 micrograms/kg if not already given</li> <li>• <b>Continuous IV salbutamol infusion</b> 1–5 micrograms/kg/min (200 micrograms/ml solution)</li> <li>• <b>IV aminophylline</b> 5 mg/kg loading dose over 20 minutes (omit in those receiving oral theophyllines) <b>followed by</b> continuous infusion 1mg/kg/hour</li> </ul> <p>Assess response before initiating each new treatment</p> |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |

## 2.5 Asthma triggers

Asthma attacks occur following exposure to a trigger factor and it is important to identify these factors on an individual level in order to tailor treatment (Levy et al., 2014). Triggers can be allergenic or nonallergenic (Gautier and Charpin, 2017). Viral infections remain the leading cause of attacks but there are other triggers such as aeroallergens, weather change and environment tobacco smoke exposure presented in box 1 (Martin et al., 2022).

### BOX 1: COMMON ASTHMA TRIGGERS

Martin et al., 2022

- Viral respiratory tract infections
- Exercise
- Weather changes in temperature and humidity
- Domestic pollutants (eg, pests, mould and dust mites)
- Environmental pollutants (eg, air pollution)
- Secondhand smoke exposure
- Pets and animals
- Strong odours
- Anxiety or strong emotions
- Drugs (eg, non-steroidal anti-inflammatory drugs and beta blockers)
- Gastro-oesophageal reflux

## 2.6 Sociocultural factors that impact on asthma management

In addition to asthma triggers there are a number of sociocultural factors which are associated with a higher risk of an asthma attack in a child or young person. These include minority ethnic groups and parental quality of life.

### 2.6.1 Ethnicity

Healthcare inequities and inequalities have been identified as a significant issue in high income countries, such as the UK, for over two decades (Jones et al., 2022). There is evidence to support a correlation between poor clinical outcomes and deprivation and literacy which is likely to be due, in part, to lower socioeconomic status being more common among some ethnic minority groups (Morris et al., 2015). This

is especially relevant for patients with allergic conditions, such as asthma, as clinical outcomes are dependent on education and empowerment of patients, and their families, self-managing their condition. The burden of allergic and autoimmune disease in the UK was recently reported comparing ethnic minority groups versus white ethnicity (Subramanian et al., 2021). From a retrospective longitudinal cohort study of 4.4 million people, Subramanian et al., found the incidence rate of asthma was only modestly higher amongst South Asians, but lower amongst Afro-Caribbean and mixed-race/other ethnicities.

It is important to also consider factors such as the differences in objective measurements and adherence to treatment between those from ethnic minorities and white patients. Data from the UK severe asthma registry and the optimum patient care research database showed that the ethnic minority population was more atopic, expressed higher type 2 inflammation markers and serum total immunoglobulin E (IgE). They also had lower lung function and worse asthma control (Busby et al., 2022a). There is further evidence from Busby et al., in another study exploring adherence in severe asthma clinical trials that patients from ethnic minority groups were less likely to adhere to treatment and had higher asthma exacerbations than white patients (Busby et al., 2022b).

It is therefore important to work in partnership with patients and their families from ethnic minorities to ensure that education resources and management plans are co-constructed and address their needs (Jones et al., 2022).

### **2.6.2 Parental quality of life**

The relationship between children and their parents' quality of life has been explored with a number of factors found to increase the risks of asthma attacks. Factors such as parental stress, health beliefs, asthma control and health literacy have been associated with decreased parental quality of life when caring for their child's asthma

(Kan et al., 2021). Some parents find the burden of managing their child's asthma personally detrimental, even among parents of children with few asthma symptoms and likely well-controlled asthma (Bellin et al., 2013). Kan et al., explored parental self-efficacy in asthma and identified three factors that improved quality of life for parents: using medications correctly, access to the reliever inhaler when their child was symptomatic, and knowing which medications to use during an asthma attack (Kan et al., 2021). Exploring parental quality of life is an important aspect of maintaining asthma control in children and young people and should be discussed by clinicians providing asthma care.

## **2.7 Asthma attack versus exacerbation of asthma**

Asthma attacks are one of the most common reasons for paediatric hospital attendance, and the incidence of severe attacks in the UK, is among the highest in Europe (Saglani et al., 2019). The terminology used to describe asthma attacks is important to ensure both clinicians and patients appreciate the potential impact of this event, which can include a risk of asthma-related death, school loss, harmful lifelong consequences for lung health, and the development of chronic obstructive pulmonary disease in adulthood (Asamoah-Boaheng et al., 2018, Fleming, 2018). A joint taskforce from the American Thoracic Society and The European Respiratory Society provided a definition on asthma exacerbations in order to standardise endpoints for clinical asthma trials and clinical practice (Reddel et al., 2009). Asthma exacerbations are events which require urgent action by both clinicians and patients to prevent serious outcomes such as hospitalisation or death from asthma. They defined a severe attack as one requiring a course of oral steroids or a hospital admission requiring oral steroids. Saglani et al., agree with this definition but also recognise this as an area for future research (Saglani et al., 2019). The term 'exacerbation' is used within clinical practice, however the definition of this, *"the process of making*

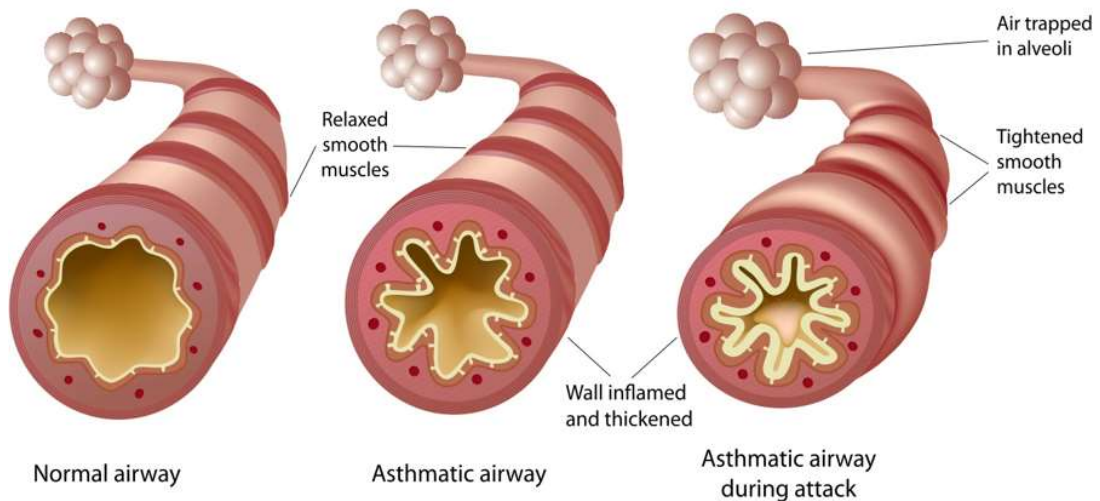
*something that is already bad even worse*" (Cambridge Dictionary, 2021) is vague when referring to asthma attacks that vary in severity. The Lancet Commission puts forward the suggestion that similarly to a myocardial infarction being referred to as a heart attack, we should use the term lung attack or asthma attack (Pavord et al., 2018). Patients, families and the leading asthma charity, Asthma UK (AUK), refer to asthma attacks rather than exacerbations. As this thesis is written around the experiences of patients and their families, the term 'attack' will be used throughout.

## **2.8 Pathophysiology of an asthma attack**

The underlying pathophysiology of an asthma attack is significant airway obstruction, as a result of smooth muscle constriction and airway plugging due to inflammation and increased mucus production, and is presented in Figure 4 (Bush and Griffiths, 2017). These airway changes give rise to increased respiratory effort and ultimately, lower oxygen saturation levels due to ventilation/perfusion mismatch (when part of the lung receives oxygen without blood flow or blood flow without oxygen). From a patient perspective, the features of an asthma attack are progressively worsening symptoms (i.e. cough, wheeze, chest tightness and difficulty with breathing). It can often be difficult for patients to gauge absolute severity when on this spectrum, as they would often successfully manage similar symptoms on this continuum with their routine treatment.

**FIGURE 4: AIRWAY CHANGES DURING AN ASTHMA ATTACK**

Available from [www.shutterstock.com/image-illustration/anatomy-asthma-74586247](https://www.shutterstock.com/image-illustration/anatomy-asthma-74586247)



## 2.9 Near-Fatal Asthma (NFA)

A NFA attack is poorly defined within the scoping review (see section 3.4.2) and asthma guidelines (see section 4.7). There are four names commonly used for this event which are interchangeable in publications: status asthmaticus (SA), severe/acute life-threatening asthma (SLTA) with progressive respiratory failure, near fatal asthma (NFA) and critical asthma syndrome (CAS) (see section 3.4.2).

### 2.9.1 Pathophysiology of a NFA attack

A NFA attack is at the furthest end of the attack spectrum, which will result in death if not recognised and then skilfully and promptly treated. As the attack progresses, either through delay in seeking medical attention, or failure to respond to emergency treatment (oral steroids, inhaled or nebulised bronchodilators), severe bronchoconstriction will occur and mucus plugging will increase. This will result in increased air trapping, poor alveolar gas exchange and worsen nonuniform ventilation (Medar et al., 2020). This will lead to blood/tissue physiological derangement with an increase in partial pressure of carbon dioxide (severe hypercarbia,  $\text{PaCO}_2$ ), a fall in partial pressure of oxygen ( $\text{PaO}_2$ ) and a fall in pH (Serrano-Pariente and Plaza, 2017,

Sekiya et al., 2016). Fatigue and a rising PaCO<sub>2</sub> cause irritability and an altered state of consciousness (Alzeer et al., 2015, Shein et al., 2016). Progressive respiratory failure and exhaustion result in a respiratory or cardiopulmonary arrest, with a high probability of invasive mechanical ventilation to prevent an asthma related death (Nievas et al., 2019, Kenyon et al., 2015).

## 2.9.2 Near-fatal asthma phenotypes

Restrepo and Peters, describe two phenotypes of NFA characterised by two distinct patterns of progression (Table 6) (Restrepo and Peters, 2008).

**TABLE 6 : NEAR-FATAL ASTHMA PHENOTYPES**

From Restrepo and Peters (2008)

| <b>Near Fatal Asthma Phenotype</b> |                           |                        |
|------------------------------------|---------------------------|------------------------|
|                                    | Gradual onset             | Sudden onset           |
| Course                             | Days                      | Hours, asphyxic asthma |
| Incidence                          | 80 – 85%                  | 15 - 20%               |
| Airway pathology                   | Gelatinous mucus plugging | No mucus plugging      |
| Predominant inflammatory cell      | Eosinophil                | Neutrophil             |
| Response to treatment              | Slow                      | Faster                 |
| Hospitalisation course             | Long                      | Short                  |
| Prevention                         | Possible                  | Undetermined           |

The most common NFA phenotype, gradual onset, affects those with severe or poorly controlled asthma and is characterised by gradual deterioration over a period of days or weeks. This type of NFA attack is responsible for a high proportion of asthma deaths, around 80–85%, however is generally considered preventable. Post-mortem examination reveals extensive airway plugging with gelatinous, dense and tenacious mucus, mixed with inflammatory and epithelial cells, epithelial denudation, mucosal oedema, and an intense eosinophilic infiltration of the submucosa (Sheehan et al., 1995, Kuyper et al., 2003). A second pattern of NFA (sudden onset) is characterised by a history of unstable asthma that is not wholly responsive to treatment. In this type of NFA, patients have acute asphyxic asthma. Respiratory failure typically develops



within two hours of the onset of symptoms. This type of presentation can result in an unexpected and sudden death (Wasserfallen et al., 1990). Post-mortem examination shows absence of mucus plugs in the large majority of patients. There are a greater proportion of neutrophils than eosinophils infiltrating the submucosa in almost all patients (Sur et al., 1993). Further research is required to try and identify interventions which may prevent sudden onset NFA attacks.

### **2.9.3 Pharmacological and non-pharmacological management of NFA**

The British Guideline on the Management of Asthma provides guidance for the management of a severe life-threatening asthma attack in children, however, does not include how to manage a near fatal attack (BTS/SIGN, 2019). The guideline offers some evidence for therapies in a critical care setting, which may include the use of anaesthetic gases and ventilatory support. The use of the anaesthetic gas Sevoflurane has proven benefits for the ventilated child. Sevoflurane inhalation enables an increase in peak inspiratory pressures which can help decrease PaCO<sub>2</sub> with clinical improvement in mechanically ventilated children (Schutte et al., Palacios et al., 2016). In addition to invasive mechanical ventilation, there is evidence to support the use of non-invasive ventilation (NIV) in acute severe asthma attacks (Smith et al., 2020, Korang et al., 2016, Mayordomo-Colunga et al., 2011). NIV is emerging as a valuable mode of ventilatory support in acute asthma, however there is considerable practice variation highlighting the need for further research and clinical guidance. Extracorporeal membrane oxygenation (ECMO) has been used on occasions in the UK for children with near-fatal asthma who are not responding to conventional treatment. ECMO is used in a final attempt to prevent an asthma-related death (Medar et al., 2020, Custer et al., 2021). There are very limited resources available with only four paediatric ECMO centres in the UK (Glenfield Hospital, Leicester; The Freeman Hospital, Newcastle; The Royal Hospital for Children,

Glasgow; and Great Ormond Street Hospital, London). Therefore, this option has limited availability.

#### **2.9.4 Risks associated with a NFA attack**

There are recognised risk factors associated with having a future NFA attack if a child or young person had a previous NFA. Compared with other children with asthma, children who have had an asthma attack severe enough to need admission to an intensive care unit (ICU), are re-admitted to hospital sooner with their next asthma attack, and have a higher rate of readmission to intensive care (Jroundi and Tse, 2021, Abu-Kishk et al., 2016) . Children who have had a NFA attack are also at a high risk of death from asthma with Triasih et al., reporting a mortality rate of almost 2% of those admitted to ICU in their study dying from an attack within a ten year period (Triasih et al., 2011) . This percentage increased to 5% if a child had required mechanical ventilation during their ICU admission. These studies highlight a need to understand the risk factors and behaviours associated with NFA attacks in order to try and reduce asthma deaths. There are no published epidemiological data on near fatal asthma or intensive care admissions with asthma in children in the UK. However, the AUKCAR have interrogated PICANet (Paediatric Intensive Care Audit Network) and identified c200 intensive care admissions per year (aged 5-16 years) where patients received mechanical support for an asthma attack (personal communication Mome Mukherjee, University of Edinburgh).

#### **2.10 Fatal Asthma**

Asthma deaths remain at unacceptably high levels despite a number of enquiries that hoped to offer solutions by identifying risk factors (Anagnostou et al., 2012, Bucknall et al., 1999). It is acknowledged that most asthma deaths are potentially avoidable, particularly those in children and young people (Levy et al., 2014). Asthma UK (Asthma UK, 2021b) report three asthma related deaths (all ages) each day across

the UK. The UK experiences the highest death rate in Europe among children and young adults (Wolfe et al., 2014, Shah and Hagell, 2019). The most recent asthma deaths enquiry within the UK was the National Review of Asthma Deaths (NRAD), commissioned by the Health Quality Improvement Partnership (Levy et al., 2014). The enquiry took place in 2012/13 over a 12-month period, with the aim of identifying key factors or reasons why children, young people and adults, continue to die from asthma. All four countries of the UK were included, and data on patients were collected from primary, secondary and tertiary care centres, ambulance services and out of hours.

There were a total of 195 deaths attributed to asthma across all ages, ten were aged < 10years and 18 were aged 10 - 19 years. Within the report, some notable factors were identified within the child and young person population (summarised in Table 7). The number of children and young people who died before reaching hospital was significant (21 CYP) and reinforced the need to better understand how these events could be prevented.

From the findings of the NRAD report there was a general prior belief that only those with severe chronic asthma die from attacks. Notably, 58% of patients who died were classed as having mild/moderate asthma, with a question raised as to whether their death was due to poorly controlled, under-treated symptoms and under-estimated risk. Poor adherence to medication, and complacency towards annual reviews, were also suggested as playing a potential role by the review. In order to maintain good asthma control, annual reviews with a primary care provider are important. The report stated 43% had not had primary care contact for review of asthma in the year prior to death. Failing to personally attend or failure to bring a child to an asthma review is a missed opportunity to reflect on asthma control, discuss trigger factors, demonstrate inhaler technique and reinforce the steps to take in the event of an attack with a supported asthma self-management plan.

**TABLE 7: KEY FACTORS AFFECTING CHILDREN AND YOUNG PEOPLE**

Adapted from the NRAD report (Levy et al., 2014)

| Feature                                                                             | < 10 years (n = 10)  | 10 – 19 years (n = 18) |
|-------------------------------------------------------------------------------------|----------------------|------------------------|
| Poor recognition of risk of adverse outcomes                                        | 70 % (PC)* 29% (SC)* | 29% (PC)* 33% (SC)*    |
| Known to social services                                                            | 14%                  |                        |
| Died before they reached hospital                                                   | 80%                  | 72%                    |
| Died between March and September inclusive                                          | 40%                  | 78%                    |
| Receiving specialist secondary care                                                 | 57%                  |                        |
| Potentially avoidable factors related to parents, their families or the environment | 90%                  | 94%                    |
| Second-hand smoke exposure                                                          | No data              | 39%                    |
| Known allergens                                                                     | No data              | 39%                    |
| Child death overview panel reports received                                         | 43%                  |                        |

\*PC – Primary Care SC – Secondary Care

There have been a number of previous asthma death reviews (Anagnostou et al., 2012, Bucknall et al., 1999, Burr et al., 1999, Jones et al., 1999, Mohan et al., 1996, Somerville et al., 1995, Wareham et al., 1993). These reviews were localised to specific regions within the UK, which may have affected the applicability of results due to differing populations, access to an emergency department within close proximity and environmental triggers. UK confidential enquiries have contributed the majority of our understanding to the factors that contribute to asthma deaths within the period 1982 – 2000 (one enquiry also from the republic of Ireland). In addition to data specific to their enquiry, all report recurrent themes and are summarised in Table 8. The recurrent themes in these reviews include poor adherence, overuse of SABA, lack of provision of asthma plans, psychosocial factors and poor inhaler technique. Ebmeier et al., reviewed the trends in asthma deaths from 1993 - 2012 across 46 countries (Ebmeier et al., 2017). Whilst not every country had complete data for this time period the researchers carried out analysis on every country that could provide a minimum

of ten years data. They were able to identify a decline in asthma deaths from the 1980's, but a stalled improvement since 2006. This finding suggests that progress made in the previous two decades (1980's and 1990's) might have slowed down. This suggests that improved implementation of current management strategies known to reduce asthma deaths is required, together with novel strategies, if a further reduction in mortality is to be achieved. In an editorial, Jenkins reports there has been some move towards eliminating asthma deaths but feels the findings of the Ebmeier et al., paper are a call for action (Jenkins, 2017). Within the AUKCAR many clinicians, affiliated clinicians and PhD students are currently working on such strategies that may show impact on data collected in the next national enquiry. Examples of published work include a systematic review on prescribing alerts for SABA use in primary care (McKibben et al., 2018), improving diagnosis in primary care using a probability approach (Daines et al., 2020) and predicting risk factors for asthma attacks in children (Buelo et al., 2018). The Chairman of the NRAD panel, Dr Mark Levy's personal reflection on the NRAD report, recommends that ways to reduce death should involve measures such as a post-attack review and the need to change clinician's attitudes towards asthma, to prevent complacency about key issues, such as education and annual reviews (Levy, 2015, Levy and Winter, 2015). NRAD researchers planned to capture qualitative data from family members affected by asthma deaths (as discussed within the report). These interviews did not take place for reasons not identified within the report. Through personal communication with Dr Levy, one of the principal reasons for this was the inability to gain ethical approval as NRAD was set up as a confidential enquiry.

The inter-relationship between acute asthma attacks, NFA and asthma death is poorly understood. NFA as a critical event in this arena, has a paucity of evidence on which to develop understanding and reduce risk. As outlined in this chapter, there is a lack of consensus definition for the event, no evidence as to their frequency and a lack of

understanding of the events from a child/young person and parent perspective. Although asthma death enquiries have taken place and there are recommendations to try and prevent them, these have lacked the patient voice. Extensive searching of the literature revealed no qualitative studies currently published which explore a near-fatal asthma attack or asthma-related death from the patient or family perspective.

**TABLE 8: SUMMARY OF CONFIDENTIAL ENQUIRIES IN UK 1982 – 2020**

| Year of enquiry publication       | Summary of report findings<br>(Location, time period, number of deaths, population)                                                                                                                                                 | Summary of report findings<br>Specific to the report                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-----------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2020<br>(Richardson et al, 2020)  | <ul style="list-style-type: none"> <li>• Republic of Ireland</li> <li>• 2006 – 2016</li> <li>• 6 deaths included in review although 11 deaths recorded in the time period</li> <li>• Children <math>\leq</math> 16 years</li> </ul> | <ul style="list-style-type: none"> <li>• 4 patients died in spring/summer 2 patients died in winter</li> <li>• All out of hospital arrest presenting to ED in asystole</li> <li>• 60% had an action plan but only 2 had been updated within the last 6 months</li> <li>• All had previous attacks the year of their death</li> <li>• No paediatric asthma nurse review/ education</li> <li>• No lung function recorded in any patient</li> <li>• No adherence data available</li> </ul> |
| 2014<br>(Levy et al., 2014)       | <ul style="list-style-type: none"> <li>• UK wide</li> <li>• 2012- 2013</li> <li>• 195 deaths</li> <li>• 28 aged <math>\leq</math>19 yrs</li> </ul>                                                                                  | <ul style="list-style-type: none"> <li>• Failure to seek help at time of attack</li> <li>• Poor adherence</li> <li>• Overuse of salbutamol</li> <li>• Social and psychological factors</li> <li>• Failure to attend review appointments</li> <li>• Lack of asthma plans</li> <li>• Failure to recognise triggers</li> <li>• Poor inhaler technique</li> </ul>                                                                                                                           |
| 2012<br>(Anagnostou et al., 2012) | <ul style="list-style-type: none"> <li>• Eastern Region in England</li> <li>• 2001 – 2006</li> <li>• 20 deaths</li> <li>• Children <math>\leq</math> 17 years</li> </ul>                                                            | <ul style="list-style-type: none"> <li>• 45% had mild to moderate asthma</li> <li>• 50% had severe asthma</li> <li>• 65% were atopic</li> <li>• 50% died between June and August</li> <li>• 60% adverse psychological and behavioural factors</li> <li>• 35% were on LABA without ICS</li> </ul>                                                                                                                                                                                        |

| Year of enquiry publication     | Summary of report findings<br>(Location, time period, number of deaths, population)                                                                                                                                            | Summary of report findings<br>Specific to the report                                                                                                                                                                                                                                                                                                        |
|---------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1999<br>(Bucknall et al., 1999) | <ul style="list-style-type: none"> <li>• Mainland Scotland</li> <li>• 1994 – 1996</li> <li>• 95 deaths</li> <li>• 5 under 16 years old</li> <li>• Aged between 15 – 64 years</li> </ul>                                        | <ul style="list-style-type: none"> <li>• Inappropriate routine management in 80% of the paediatric deaths</li> <li>• Overuse salbutamol</li> <li>• Underuse of inhaled steroids</li> <li>• Psychosocial problems notably depression</li> <li>• Poor compliance</li> <li>• Lack of PEF monitoring</li> </ul>                                                 |
| 1999<br>(Burr et al., 1999)     | <ul style="list-style-type: none"> <li>• Wales</li> <li>• 1994</li> <li>• 52 deaths</li> <li>• 0 – 14 years – 2 deaths</li> <li>• 15 – 44 years – 14 deaths</li> <li>• 45 – 64 years – 36 deaths</li> </ul>                    | <ul style="list-style-type: none"> <li>• 61% occurred in the patient's home</li> <li>• 15% occurred in transit or on arrival to hospital</li> <li>• 40% admitted to hospital in the previous year</li> <li>• 32% had mild to moderate asthma</li> <li>• multiple social and psychosocial factors</li> <li>• 28% inappropriate medical management</li> </ul> |
| 1999<br>(Jones et al., 1999)    | <ul style="list-style-type: none"> <li>• 5 districts of the Northern Health Region in England</li> <li>• 1994 – 1996</li> <li>• 33 deaths</li> <li>• 76% &lt; 65yrs</li> <li>• 17/33 had significant co morbidities</li> </ul> | <ul style="list-style-type: none"> <li>• Asthma death certification in &gt;65yrs are very unreliable</li> <li>• Errors of judgement, compliance and psychosocial disruption exerted an additional adverse influence in an important minority of cases</li> </ul>                                                                                            |
| 1996<br>(Mohan et al., 1996)    | <ul style="list-style-type: none"> <li>• East Anglia.</li> <li>• 1992 – 1996</li> <li>• 34 deaths</li> <li>• Aged &lt;65 years</li> <li>• 2 under the age of 20years</li> </ul>                                                | <ul style="list-style-type: none"> <li>• Adverse social and psychological factors identified in 27 of the patients</li> </ul>                                                                                                                                                                                                                               |



| Year of enquiry publication                   | Summary of report findings<br>(Location, time period, number of deaths, population)                                                                          | Summary of report findings<br>Specific to the report                                                                                                                                                                                                                                                                                                                                                                                 |
|-----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1995<br>(Somerville et al., 1995)             | <ul style="list-style-type: none"> <li>• Mersey Region</li> <li>• 1989 – 1990</li> <li>• 43 deaths</li> <li>• Aged 16 – 65 years</li> </ul>                  | <ul style="list-style-type: none"> <li>• Avoidable factors in 67% – lack of assessment, inadequate doses of steroids, overuse of salbutamol</li> <li>• 51% at high risk of a respiratory death</li> </ul>                                                                                                                                                                                                                            |
| 1993<br>(Wareham et al., 1993)                | <ul style="list-style-type: none"> <li>• Norwich</li> <li>• 1988 - 1991</li> <li>• 24 deaths</li> <li>• Aged between 16 and 65</li> </ul>                    | <ul style="list-style-type: none"> <li>• 71% had rapid onset of symptoms leading to death in under three hours</li> <li>• 71% had social or psychosocial factors considered to be important</li> <li>• Inappropriate treatment, lack of written asthma action plans and inappropriate asthma care were identified as contributing factors</li> </ul>                                                                                 |
| 1982<br>(British Thoracic Association, 1982). | <ul style="list-style-type: none"> <li>• West Midland and Mersey Regions</li> <li>• 1979</li> <li>• 90 patients</li> <li>• Aged between 15 and 65</li> </ul> | <ul style="list-style-type: none"> <li>• Previous severe attacks</li> <li>• Undertreated with inhaled steroids</li> <li>• Some patients were steroid naïve</li> <li>• 46% adherence</li> <li>• 79% dead within 24 hours</li> <li>• 85% died at home or at work with 65% of that cohort dying without medical attention</li> <li>• Failure to recognise asthma severity</li> <li>• 86% had potentially preventable factors</li> </ul> |

## **2.11 Aims and objectives of this PhD**

The overarching aim of this study was to define NFA and identify potential modifiable behaviours to reduce the risk of NFA and an asthma-related death. This PhD study was sub-divided into two components:

- A scoping review, an asthma guideline review and an eDelphi study to identify a consensus definition of NFA
- Qualitative interviews to explore parents' and young adults' perspectives of fatal and near-fatal asthma.

Component one aimed to:

- Gain an international clinical consensus name and definition for a 'critical asthma attack' to enable the frequency of defined attacks to be measured, against which future interventions can be trialled to reduce these and asthma deaths.
- Utilise the consensus name and definition to identify participants for the NFA qualitative study

The scoping review and asthma guideline reviews contained chapter aims.

- The aims of the scoping review were to identify features of a critical asthma attack reported in the literature that included: names and definitions; clinical features (signs and symptoms); objective physiological measurements and patient/ parent/carer experience of the attack.
- The aims of the asthma guidelines review were to identify guidelines worldwide and compare definitions and management of acute asthma attacks across the spectrum of severity including NFA.

Component two aimed to:

- Identify key time-critical experiences of those who have experienced NFA (or their parents) that may provide a window of opportunity to seek help

- Understand family circumstances and behaviours that may place children and young people at greater risk of asthma death/near fatal asthma
- Understand the long-term psychosocial consequences of NFA
- Use these findings to inform key stakeholders such as education, primary care, severe asthma registries and emergency service responses, in order to reduce the risks of fatal and near-fatal asthma and provide appropriate support for CYP and their families

In order to achieve these aims, interviews were carried out to give the opportunity to parents of children and young adults who have experienced NFA attacks and bereaved parents of children who have suffered a fatal attack, to describe their experience.

## **2.12 Underpinning theory in qualitative research**

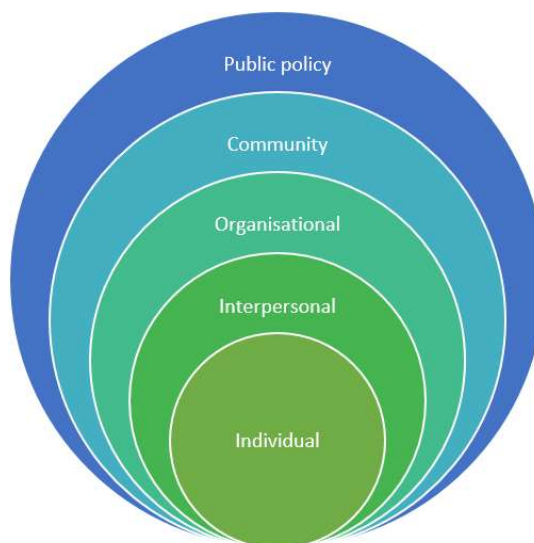
Theories provide complex and comprehensive conceptual understandings of phenomena and can be used to explore various lines of enquiry such as human behaviour/ interactions or how organisations operate (Reeves et al., 2008). Reeves et al., further explain theories give researchers an alternative approach to look at complex problems and social issues, focusing their attention on different aspects of the data and providing a framework within which to conduct their analysis. There are a number of different theories which could be applied to this study which include socio-ecological model, candidacy framework or a theory related to grief (Dixon-Woods et al., 2006, Parkes & Prigerson, 2013, Kubler-Ross, 1989). Through discussion with my supervisors, I have chosen the socio-ecological model as the underpinning framework for this thesis. The rationale for this decision stems from further reading and appreciation that this model considers the complex interplay between the individual, their relationships, community, organisations and public policy. Applying this model to a study of near-fatal and fatal asthma attacks allows us to understand

the range of factors that put individuals at risk of these attacks and may offer insight on ways to prevent asthma deaths in the future. It is also important to consider how factors at one level influence factors at another level and how imperative it would be to act across multiple levels of the model at the same time to make a difference in outcomes for children and young people. It is interesting to note that one of the studies on asthma management in British South Asian Children used both a candidacy framework and the socioecological model in understanding the barriers to effective and accessible asthma care (Hudson et al., 2016). This would be interesting to explore in future qualitative work.

### **2.12.1 Socio-ecological model**

The socio-ecological model was first introduced as a conceptual model for understanding human development by Bronfenbrenner in the 1970s and later formalised as a theory in the 1980s (Kilanowski, 2017). When considering this model to explore a medical condition such as asthma, Kilanowski further explains how the socio-ecological model states that health is affected by the interaction between the characteristics of the individual, the community, and the environment that includes the physical, social, and political components. The socio-ecological model has previously been used as a framework for studies on asthma. Studies, as examples, have explored asthma friendly schools, the development of a programme to manage asthma tailored to the needs of children and their families of South Asian origin and asthma adherence in adolescents and young adults (Nuss et al., 2016, Lakhanpaul et al., 2014, Zaeh, 2022). The socio-ecological model (figure 5) provides a holistic approach for interventions as it ensures that structural, individual and interpersonal factors are considered (Lakhanpaul et al., 2014).

**FIGURE 5 SOCIAL ECOLOGICAL MODEL DISPLAYING THE MULTILEVEL FACTORS**  
Lakhanpaul et al., 2014



It is important to let the data from the qualitative studies 'speak for itself' however I will utilise the socioecological framework within the discussion (chapter nine) and to structure the recommendations for future practice (chapter ten).

### **2.13 Summary and next steps.**

Asthma is one of the most common long-term conditions in children. Despite advances in the understanding of the mechanisms of asthma, asthma attacks and asthma-related deaths remain problematic. Within this chapter I have examined available data from clinical studies, both within the UK and from a wider global context. It is apparent that while there are a variety of treatments available to clinicians for NFA attacks, there may be a number of external pre-intervention elements of which only parents/ carers and young adults are aware. There is however a paucity of qualitative data that explores the patient or caregiver perspective of these events. This PhD programme of work was undertaken to explore the experiences of those affected by fatal and NFA attacks and to identify key time-critical events and behaviours that may enable clinicians to intervene or work with patients and their families to reduce future

risk. In the next chapter, I will present the findings of a scoping review that identifies names, definitions and features relating to a critical asthma attack in children, adolescents and young adults which, if not treated appropriately, could result in a fatal attack.

## **3 Chapter three – Scoping review**

### **3.1 Introduction**

The first aim of my thesis was to conduct a scoping review of the literature relating to NFA to help inform the questions for the eDelphi (see chapter five). This chapter reports the methodology and findings of a scoping review. This review identified the names, definitions and features relating to a critical asthma attack in children, adolescents and young adults. Asthma guidelines, such as GINA and BTS/SIGN, categorise the severity of asthma attacks into mild, moderate, severe and life threatening (GINA, 2019, BTS/SIGN, 2019). I will refer to the term ‘critical asthma attack’ to describe this event, as outlined in my note on terminology in Chapter One (see section 1.5). A ‘critical asthma attack’ was considered as an attack which was at the furthest end of the spectrum of attacks, which if it was not recognised by the individual, parent or carer and then skilfully and promptly treated by a clinical team, would result in death.

### **3.2 Aims**

The aims of this scoping review were to identify features of a critical asthma attack reported in the literature that included:

- names and definitions
- clinical features (signs and symptoms)
- objective physiological measurements
- patient/ parent/carer experience of the event in a child (over 5 years), adolescent and young adult (up to age 24 years) population.

### **3.3 Methods**

When considering how to perform a literature review to support my PhD thesis, I met with a senior university librarian, Marshall Dozier (MD), to discuss the aims of my thesis. We noted two previous systematic reviews had been carried out identifying

clinical risk factors and psychological risk factors associated with near-fatal and fatal asthma (Alvarez and Fitzgerald, 2007, Alvarez et al., 2005). We were unable to find any published literature on either parent or patient perspective of a NFA or fatal attack. Grant and Booth provide a typology of literature reviews currently being utilised in health and health care domains (Grant and Booth, 2009). I considered a scoping review, a mapping review and a rapid review. I rejected the idea of conducting either a mapping review or a rapid review. The aim of a mapping review is to map out and categorise existing literature on a particular topic, with further review work expected (Grant and Booth, 2009). Through further reading and discussion around mapping reviews, I felt this method lacked the synthesis and analysis of other approaches. A rapid review is conducted within a timescale by using systematic review methods to search and critically appraise existing research (Beecher et al., 2020). I felt this type of review would limit the search and would potentially restrict the findings in terms of names of the critical asthma attack and features of this attack to inform the eDelphi. Referring to the review ready reckoner developed by Booth, a scoping review has a narrow, partially focused question which is conducted in a short timescale (Figure 6) (Booth, 2016). After discussion with my supervisors I decided to scope the current literature relating to near fatal asthma and use the findings to help inform the first round of the eDelphi questionnaire (see Chapter 5). Although I conducted aspects of the scoping review as a single reviewer, my supervisors were involved at all five stages of the process.



**FIGURE 6: ADAPTED FROM REVIEW READY RECKONER - ASSESSMENT TOOL (RRRSAT)**  
(Booth, 2016)

| Factor                      | Evidence Briefing                                                                                                          | Mapping Review                                                                             | Scoping Review                                                                                  | Rapid Evidence Assessment                                                                                    | Rapid Realist Review                                                                 | Systematic Review (Attitudes)                                                                    | Systematic Review (Effects)                              | Review of Reviews                                                                                                                                    |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|----------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>R</b><br>Review question | Narrow Focused Question                                                                                                    | Broad Question Anchored by One or More Elements                                            | Narrow Partially Focused Question                                                               | Narrow Focused Question                                                                                      | Starts with Narrow Question, often extended by Analogy/Theory                        | Narrow Question Co-terminous with Effects Question OR Broader Question on Phenomenon             | Narrow Focused Question                                  | Broad Question Typically Focused on Two or Three Common Elements                                                                                     |
| <b>E</b><br>Epistemology    | Seeks to depict an Objective Reality through a judicious, pragmatic and yet representative body of best available evidence | Seeks to acknowledge multiple possible Perspectives within the constraints of Practicality | Seeks to interpret an initial question through a reconciliation of Relatedness and Practicality | Seeks to maintain Distance and Impartiality when examining programmes/ interventions within a Policy Context | Seeks to convey that Outcomes are dependent on the Context in which they are sought. | Seeks to achieve Proximity to Views of Participants and thereby imbue Findings with Authenticity | Seeks to describe Objective Causality (Cause and Effect) | Seeks to reconcile multiple "Objective" yet occasionally conflicting perspectives through explanations of method, study quality and included studies |
| <b>T</b><br>Time/Timescale  | 2 weeks                                                                                                                    | 4-16 weeks                                                                                 | 8 weeks OR 24 weeks                                                                             | 8-24 weeks                                                                                                   | 8-24 weeks                                                                           | 36-52 weeks                                                                                      | 52-78 weeks                                              | 12-24 weeks                                                                                                                                          |
| <b>R</b><br>Resources       | Single Reviewer Limited Databases                                                                                          | Single Reviewer Comprehensive Databases (may be Sampled)                                   | Single Reviewer Limited Databases                                                               | Double Reviewer Limited Databases                                                                            | Double Reviewer Limited Databases                                                    | Double Reviewer Comprehensive or Purposive Databases                                             | Double Reviewer Comprehensive Databases                  | Double Reviewer Comprehensive Databases                                                                                                              |

The five stage scoping review process (Table 9) proposed by Arksey and O'Malley with adaptations by Levac et al., and the Joanna Briggs Institute, were adopted (Arksey and O'Malley, 2005, Levac et al., 2010, Peters et al., 2015). A recently published checklist was also utilised to ensure inclusion of all the relevant information required to complete a comprehensive scoping review (Tricco et al., 2018).

**TABLE 9: THE FIVE STAGE SCOPING REVIEW PROCESS**

From Arksey and O'Malley (Arksey and O'Malley, 2005).

| Stage   | Explanation of the stage                         |
|---------|--------------------------------------------------|
| Stage 1 | identifying the research question                |
| Stage 2 | identifying relevant studies                     |
| Stage 3 | study selection                                  |
| Stage 4 | charting the data                                |
| Stage 5 | collating, summarising and reporting the results |

### 3.3.1 Stage 1: Identifying the research questions

A number of research questions were identified following consideration of the aims of the review (section 3.2):

- What name is used to describe this critical asthma attack?
- How is this attack defined?
- What are the key clinical features of this attack?
- What are the key objective measurements of this attack?
- What other features are described during this attack?
- Are there any differences identified if the research team are from Emergency Department (ED), Respiratory (R) or Critical Care (CC) medicine?
- Is there a parent/ carer/ patient perspective available to describe this critical asthma attack?

### **3.3.2 Stage 2: Identifying relevant studies**

The following inclusion and exclusion criteria were developed through discussion with supervisors Steve Cunningham (SC) and Louise Fleming (LF). The discussion took into account the aims of the scoping review and how the findings from the review would inform the questions in the first round of the eDelphi study (section 5.8).

Inclusion criteria, any of the following:

- A name for the attack
- A definition of the attack
- Presence of clinical signs or objective measurements

Exclusion criteria, any of the following:

- Lack of definition
- Lack of clinical features or objective measurements
- Predominant adult population (mean age of participants > 25 years).
- Grey literature
- Available as abstract only
- Not written in English

For studies which related to patient experience the following inclusion and exclusion criteria was used:

Inclusion criteria

- Patient/ parent/ carer experience of the event in children, adolescents or young adults within title, abstract or full text.

Exclusion criteria

- Absence of patient/ parent/ carer experience of the event in children, adolescents or young adults within title, abstract or full text.
- Grey literature
- Available as abstract only
- Not written in English

### **3.3.3 Search strategies and databases**

A literature search of four databases, Pubmed, Web of Science, Embase and CINAHL plus, was conducted using search terms for the population and severity of attack (Box 1). The terms used for the severity of the attack were agreed through discussion with SC, LF and MD. Filters were applied for human studies, full text and written in English due to limited resources to translate studies. No filters were applied for number of years to search. The earliest papers identified for this search commenced in 1960. Global asthma guidelines were not included, as guidance on features and pharmacological management tended to be limited to life threatening asthma and this will be explored in chapter four. Grey literature (social media posts, blogs and newspaper articles) was not included in this review. This would be an area which should be considered for future research.

**Box 2: SEARCH STRATEGY USED TO IDENTIFY STUDIES FROM 4 DATABASES**

Child\* OR pediater\* OR paediatric\* OR Adolescen\* OR young adult

AND

“near fatal asthma” OR “status asthmaticus” OR “life threatening asthma” OR “acute asphyxia asthma”

Human studies, full text , English

**3.3.4 Stage 3: Study selection**

All eligible studies identified from the initial search underwent title and abstract screening, which I undertook. This was followed by a full text review of potentially relevant articles. I also included a search of the referenced studies within the identified studies, however these did not yield additional studies for review. Studies selected for review were frequently discussed at supervision meetings with SC. This was to ensure consistency with studies for inclusion and exclusion, and to resolve uncertainty.

**3.3.5 Stage 4: Charting the data**

Charting tables were developed to record and assimilate extracted data from the studies included in this review, and were subject to several iterations. Tables were created to capture findings relating to the name, definition, clinical features and objective measurements, where the following headings were used:

- A. Author(s)/ Year of publication
- B. Origin (country the study was conducted)
- C. Study design
- D. Clinical team undertaking the study Emergency Department (ED)/  
(Respiratory (R) / Critical Care (CC))
- E. Population - child only or mixed child / adult study

### **3.3.6 Stage 5: Collating, summarising and reporting the results**

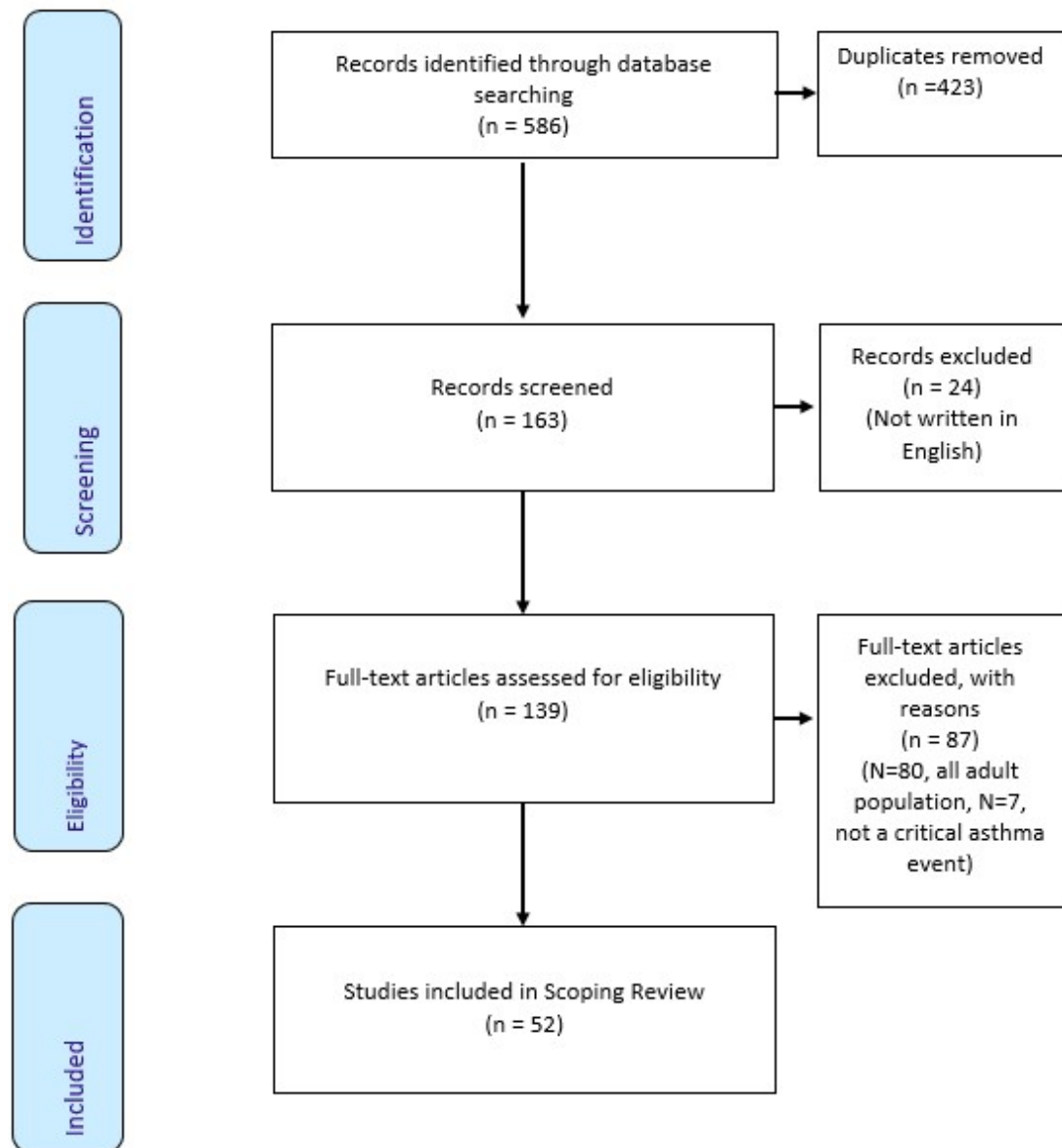
Levac et al (2010) recommend that this stage is broken into three steps.

- Descriptive analysis – the data from the literature search was mapped describing the number of studies included, years of publication, discipline within which the study was conducted (ED/ R/ CC), characteristics of the study populations, and countries where studies were conducted.
- Reporting results – results were presented using tables ensuring the research questions in stage one (see section 3.3.1) were answered.
- Consideration of the meaning of the results – the results from this scoping review were used to inform the first round of the eDelphi questionnaire (see section 5.8)

## **3.4 Results**

The flow chart diagram (Figure 7) details the search and study selection processes, which, took place between April 2017 and May 2017. An additional search was conducted in December 2019, which yielded one additional paper, which was included in this scoping review. This study is included within the flowchart.

**FIGURE 7: FLOW CHART DIAGRAM OF SCOPING REVIEW**



An initial search identified 586 studies from the four databases. After duplicates (n= 423) were removed 163 studies were screened. Those not written in English (n=24) were removed at title and abstract stage leaving 139 full text articles to be assessed for eligibility. Those not meeting inclusion criteria, adult papers with the mean age of participants > 45 years (n=80) or the critical asthma attack was not of the appropriate severity (n=7), were excluded from reading of full text (n = 87). Overall 52 studies were included in the scoping review to answer the research questions. I carried out

a full text review all of the eligible studies. After the full text review data were extracted from all selected studies including author(s), year of publication, country of origin, discipline of research team (ED, R, CC) and type of publication (cohort study, case review or expert opinion). Papers were included that contained at least one of the following: name of the event, defined the event, contained clinical features, objective measures or patient/ parent perspective. The extracted data were discussed with SC in supervision meetings. Any differences in opinion (e.g. inclusion of papers pre inhaled steroids) were resolved by consensus. The papers identified pre inhaled steroids were included as despite advances in options to treat asthma, some patients use SABA as a monotherapy.

### 3.4.1 Geography of studies included

Studies were identified from 13 countries (Table 10). The majority of studies (65%) were from the USA (n=34/52). The studies were from three disciplines; Respiratory medicine (n=18/52, 35%), Critical Care (n=31/52, 60%) and Emergency Department (n=1/52, 2%). The disciplines of two manuscripts could not be determined (n=2/52, 4%).

**TABLE 10: GEOGRAPHY OF INCLUDED STUDIES.**

| Country      | Number of studies | Percentage of studies (%*) |
|--------------|-------------------|----------------------------|
| Argentina    | 1                 | 2                          |
| Australia    | 1                 | 2                          |
| China        | 1                 | 2                          |
| Canada       | 5                 | 10                         |
| Germany      | 2                 | 4                          |
| Ireland      | 1                 | 2                          |
| Japan        | 1                 | 2                          |
| Netherlands  | 1                 | 2                          |
| New Zealand  | 2                 | 4                          |
| Saudi Arabia | 1                 | 2                          |
| Spain        | 2                 | 2                          |
| USA          | 34                | 65                         |
| All          | 52                | 99                         |

\*% rounded to the nearest whole number

### **3.4.2 Name of the critical asthma attack**

Within this scoping review four names were identified for the critical asthma attack: status asthmaticus (SA) (n=28/52), severe/ acute life threatening asthma (SLTA) with progressive respiratory failure (n=5/52), near-fatal asthma (NFA) (n=15/52) and critical asthma syndrome (CAS) (n=1/52). Critical asthma syndrome was a novel term and was used by one author as an umbrella term for acute severe asthma, refractory asthma, status asthmaticus, and near-fatal asthma (Kenyon et al., 2015). A subset referred to as acute asphyxial asthma (AAA) (n=2/52), a condition more prevalent in adults and a recognised phenotype of NFA, was also described in children (Martchek et al., 2015, Maffei et al., 2004). There appears to have been an evolution of terminology from status asthmaticus to severe life threatening asthma to the most recent term, near-fatal asthma. The name used can however be interchangeable depending on the author.

### **3.4.3 Definitions of name used to describe the critical asthma attack.**

Definitions of this attack or criteria used to recruit to cohort studies were offered by 36 authors (n=36/52). Some authors declared a definition during a review article using expert opinion (n= 9/36) whilst others declared a definition to support cohort recruitment (n=16/36). Some authors declared a definition to place a case study in context (n=11/36) which included the case studies of the AAA subset (n=2/11) (Table 11).

Within the definitions authors recognised failure to respond to treatment (n=18/36) as a key feature which leads to a rising PaCO<sub>2</sub> (n=12/36), a falling pH<sup>1</sup> (n=2/36) and subsequently resulted in cardio/ respiratory arrest (n=3/36). Mechanical ventilation

<sup>1</sup> pH is power of Hydrogen. pH is a scale used to specify the acidity and basicity of an aqueous solution.



(n=9/36) was necessary due to either a rising PaCO<sub>2</sub> (instigated to prevent further deterioration) or cardiopulmonary arrest.

**TABLE 11: NAMES AND DEFINITIONS USED TO REPRESENT CRITICAL ASTHMA ATTACK IN CHRONOLOGICAL ORDER.**

| Author(s) / year                     | Origin (country) | Clinical Team (Respiratory (R)/ Critical Care (CC)/ Emergency Department (ED) | Population child (C) mixed (M) | Name Status Asthmaticus (SA), Severe Life Threatening Asthma (SLTA), Near Fatal Asthma (NFA) Critical Asthma Syndrome (CAS) or subset Acute Asphyxia Asthma (AAA) | Definition                                                                                                                                                                                                                                                                                                                          |
|--------------------------------------|------------------|-------------------------------------------------------------------------------|--------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>COHORT STUDIES</b>                |                  |                                                                               |                                |                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                                     |
| Serrano-Pariente, J., Plaza V (2017) | Spain            | R                                                                             | M                              | NFA                                                                                                                                                               | <i>“dyspnea that prevents speech, decreased level of consciousness, hypercapnia (in general, PaCO<sub>2</sub>&gt; 45–50 mmHg), admission to an ICU, respiratory or cardiopulmonary arrest, orotracheal intubation, and mechanical ventilation”.</i>                                                                                 |
| Sekiya, K., et al. (2016).           | Japan            | R                                                                             | M                              | SLTA                                                                                                                                                              | <i>“inability to move because of dyspnoea. Abasia, difficulty in speaking, and objective findings (peak expiratory flow &lt; 60%, SpO<sub>2</sub> &lt; 90%, partial pressure of oxygen in arterial blood (PaCO<sub>2</sub>) ≤ 60 mmHg, and partial pressure of carbon dioxide in arterial blood (PaCO<sub>2</sub>) ≥ 45 mmHg)”.</i> |
| Serrano-Pariente, J., et al. (2015). | Spain            | R                                                                             | M                              | NFA                                                                                                                                                               | <i>“as a severe asthma exacerbation accompanied by at least one of the following: (i) respiratory arrest; (ii) requirement for mechanical ventilation (MV); and (iii) hypercapnia (arterial carbon dioxide tension of &gt;50 mmHg) and/or acidosis (pH of &lt;7.30)”.</i>                                                           |
| Schutte, D., et al. (2013).          | Netherlands      | CC                                                                            | C                              | SLTA                                                                                                                                                              | <i>“mechanical ventilation”.</i>                                                                                                                                                                                                                                                                                                    |
| Newth, C. J. L., et al. (2012).      | USA              | CC                                                                            | C                              | NFA                                                                                                                                                               | <i>“received endotracheal intubation and ventilation”</i>                                                                                                                                                                                                                                                                           |
| Carroll, C. L., et al. (2010).       | USA              | CC                                                                            | C                              | NFA                                                                                                                                                               | <i>“as an exacerbation requiring ICU admission”</i>                                                                                                                                                                                                                                                                                 |
| Nannini, L. J., et al. (2007).       | Argentina        | R                                                                             | M                              | NFA                                                                                                                                                               | <i>“oroatracheal intubation due to respiratory arrest during an asthma attack or acute respiratory acidosis with hypercapnia &gt;45 mmHg”.</i>                                                                                                                                                                                      |

| Author(s) / year                 | Origin (country) | Clinical Team (Respiratory (R)/ Critical Care (CC)/ Emergency Department (ED) | Population child (C) mixed (M) | Name<br>Status Asthmaticus (SA), Severe Life Threatening Asthma (SLTA), Near Fatal Asthma (NFA) Critical Asthma Syndrome (CAS) or subset Acute Asphyxia Asthma (AAA) | Definition                                                                                                                                                                                                                                                                    |
|----------------------------------|------------------|-------------------------------------------------------------------------------|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Yao, T. C., et al. (2003).       | China            | R                                                                             | C                              | NFA                                                                                                                                                                  | <i>"who either had histories of hospital admission requiring intubation and ventilation for acute exacerbation of asthma symptoms or had experienced hypercapnic respiratory failure during an acute asthmatic episode with a PaCO<sub>2</sub> of &gt;45 mm Hg".</i>          |
| Julius, S. M., et al. (2002).    | USA              | R                                                                             | C                              | SLTA                                                                                                                                                                 | No definition provided                                                                                                                                                                                                                                                        |
| Mitchell, I., et al. (2002).     | Canada           | R                                                                             | C                              | NFA                                                                                                                                                                  | <i>"required assisted ventilation in an ICU"</i>                                                                                                                                                                                                                              |
| Schmitz, T., et al. (2000).      | Germany          | R                                                                             | C                              | NFA                                                                                                                                                                  | <i>"mechanical ventilation (near-fatal attacks) due to symptomatic respiratory obstruction caused by chronic asthma, recurrent wheezy bronchitis or a first asthma attack in children of &lt;16 years".</i>                                                                   |
| Martin, A. J., et al. (1995).    | Australia        | R                                                                             | C                              | NFA                                                                                                                                                                  | <i>"asthma causing respiratory arrest, a PaCO<sub>2</sub> above 50 mm Hg and/or an altered state of consciousness or inability to speak on presentation to hospital".</i>                                                                                                     |
| Richards, G. N., et al. (1993).  | New Zealand      | R                                                                             | M                              | SLTA                                                                                                                                                                 | No definition provided                                                                                                                                                                                                                                                        |
| Cox, R. G., et al. (1991).       | Canada           | CC                                                                            | C                              | SA                                                                                                                                                                   | <i>"small group of severe asthmatics who present with severe bronchospasm and CO<sub>2</sub> retention, who develop respiratory muscle fatigue to the point of exhaustion, fail to respond to intensive medical therapy, and require a period of mechanical ventilation".</i> |
| Zimmerman, J. E., et al. (1990). | New Zealand      | CC                                                                            | C                              | SLTA                                                                                                                                                                 | No definition provided                                                                                                                                                                                                                                                        |
| Bohn, D., et al. (1984).         | Canada           | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                                                                                                        |
| Herman, J. J., et al. (1983).    | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                                                                                                        |

| Author(s) / year                      | Origin (country) | Clinical Team (Respiratory (R)/ Critical Care (CC)/ Emergency Department (ED) | Population child (C) mixed (M) | Name<br>Status Asthmaticus (SA), Severe Life Threatening Asthma (SLTA), Near Fatal Asthma (NFA)<br>Critical Asthma Syndrome (CAS) or subset Acute Asphyxia Asthma (AAA) | Definition                                                                                                                                                                                                                            |
|---------------------------------------|------------------|-------------------------------------------------------------------------------|--------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Shapiro, G. G., et al. (1974).        | USA              | R                                                                             | C                              | SA                                                                                                                                                                      | <i>"the lack of response of severe bronchospasm to a series of three subcutaneous injections of 1:1,000 aqueous epinephrine given at 15 minute intervals"</i>                                                                         |
| Pierson, W. E., et al. (1974)         | USA              | R                                                                             | C                              | SA                                                                                                                                                                      | <i>"the failure of bronchial response to three subcutaneous injections of 0.2 to 0.5ml 1:1,000 aqueous epinephrine at 15 minute intervals"</i>                                                                                        |
| Kampschulte, S., et al. (1973).       | USA              | CC                                                                            | C                              | SA                                                                                                                                                                      | <i>"bronchodilator- resistant diffuse wheezing with signs of asphyxia"</i>                                                                                                                                                            |
| Downes, J. J., et al. (1973).         | USA              | CC                                                                            | C                              | SA                                                                                                                                                                      | <i>" an allergic history, bilateral intense wheezing, thoracic hyperinflation and no clinical improvement after two subcutaneous injections of aqueous epinephrine (0.01mg/kg) within a 30 min period"</i>                            |
| Wood, D. W., et al. (1972).           | USA              | CC                                                                            | C                              | SA                                                                                                                                                                      | No definition provided                                                                                                                                                                                                                |
| <b>CASE REPORTS</b>                   |                  |                                                                               |                                |                                                                                                                                                                         |                                                                                                                                                                                                                                       |
| Alzeer, A. H., et al. (2015).         | Saudi Arabia     | CC                                                                            | C                              | NFA                                                                                                                                                                     | <i>"often results in profound hypoxemia, hypercapnia, and altered mental status"</i>                                                                                                                                                  |
| Martchek, M. A., et al. (2015).       | USA              | ED                                                                            | C                              | AAA                                                                                                                                                                     | <i>"abrupt onset of respiratory failure secondary to asthma".</i>                                                                                                                                                                     |
| Carrie, S. and T. A. Anderson (2015). | Canada           | CC                                                                            | C                              | SA                                                                                                                                                                      | <i>"an acute, intractable asthma attack refractory to standard interventions that can lead to progressive respiratory failure".</i>                                                                                                   |
| Quizon, A. and E. Forno (2014).       | USA              | R                                                                             | C                              | SLTA                                                                                                                                                                    | <i>"the condition of a patient in progressive respiratory failure due to asthma in whom conventional forms of therapy have failed; for clinical purposes, a patient not responding to initial doses of nebulized bronchodilators"</i> |
| Maffei, F. A., et al. (2004).         | USA              | CC                                                                            | C                              | AAA                                                                                                                                                                     | <i>"brief duration of symptoms (usually &lt;6 hours), few identifiable triggers, and a rapid progression to respiratory failure".</i>                                                                                                 |

| Author(s) / year                       | Origin (country) | Clinical Team (Respiratory (R)/ Critical Care (CC)/ Emergency Department (ED) | Population child (C) mixed (M) | Name<br>Status Asthmaticus (SA), Severe Life Threatening Asthma (SLTA), Near Fatal Asthma (NFA) Critical Asthma Syndrome (CAS) or subset Acute Asphyxia Asthma (AAA) | Definition                                                                                                                                                                                |
|----------------------------------------|------------------|-------------------------------------------------------------------------------|--------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Kaelin, M. and R. L. Morton (2002).    | USA              | CC                                                                            | C                              | NFA                                                                                                                                                                  | No definition provided                                                                                                                                                                    |
| Siddiqi, A. and V. Bandi (1999).       | USA              | CC                                                                            | C                              | NFA                                                                                                                                                                  | <i>“as acute asthma associated with a respiratory arrest or arterial carbon dioxide tension of more than 50 mm Hg, with or without altered consciousness”</i>                             |
| Niggemann, B. and U. Wahn (1992).      | Germany          | CC                                                                            | C                              | NFA                                                                                                                                                                  | No definition provided                                                                                                                                                                    |
| Otte, R. W. and P. Fireman (1991).     | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | <i>“the patient is not responding to customary doses of beta-agonists and theophylline”</i>                                                                                               |
| Gluck, E. H., et al. (1990).           | USA              | CC                                                                            | M                              | SA                                                                                                                                                                   | <i>“the penultimate event in a complex cascade of pathologic processes including diffuse airway inflammation, bronchoconstriction, and abnormal ventilation/perfusion relationships.”</i> |
| Levin, N. and J. B. Dillon (1972)      | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                    |
| Rhine, E. J. and J. K. Rosales (1970). | Canada           | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                    |
| Wood, D. W., et al. (1968).            | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                    |
| Downes, J. J., et al. (1968).          | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | <i>“The failure of severe wheezing to improve following two successive subcutaneous injections of aqueous epinephrine given within 30 minute period”</i>                                  |
| Strauss, J., et al. (1966).            | USA              | unknown                                                                       | C                              | SA                                                                                                                                                                   | <i>“Epinephrine-fast state in an acutely ill asthmatic patient”</i>                                                                                                                       |
| Misuraca, L. (1966).                   | USA              | CC                                                                            | M                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                    |
| Downes, J. J., et al. (1966).          | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | <i>“Acute, severe, epinephrine resistant wheezing”</i>                                                                                                                                    |
| Beam, L. R., et al. (1965)             | USA              | CC                                                                            | C                              | SA                                                                                                                                                                   | No definition provided                                                                                                                                                                    |

| Author(s) / year                      | Origin<br>(country) | Clinical Team<br>(Respiratory<br>(R)/ Critical<br>Care (CC)/<br>Emergency<br>Department<br>(ED) | Population<br>child (C)<br>mixed (M) | Name<br>Status Asthmaticus<br>(SA), Severe Life<br>Threatening Asthma<br>(SLTA), Near Fatal<br>Asthma (NFA)<br>Critical Asthma<br>Syndrome (CAS) or<br>subset Acute<br>Asphyxia Asthma<br>(AAA) | Definition                                                                                                                                                                                                                          |
|---------------------------------------|---------------------|-------------------------------------------------------------------------------------------------|--------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bukantz, S. C. (1963).                | USA                 | R                                                                                               | C                                    | SA                                                                                                                                                                                              | No definition provided                                                                                                                                                                                                              |
| McNicholl, B. (1960)                  | Ireland             | unknown                                                                                         | C                                    | SA                                                                                                                                                                                              | No definition provided                                                                                                                                                                                                              |
| <b>EXPERT OPINION</b>                 |                     |                                                                                                 |                                      |                                                                                                                                                                                                 |                                                                                                                                                                                                                                     |
| Shein, S. L., et al.<br>(2016).       | USA                 | CC                                                                                              | C                                    | NFA                                                                                                                                                                                             | <i>“critical asthma with progressive respiratory failure, fatigue, and altered consciousness that requires endotracheal intubation and mechanical ventilation”.</i>                                                                 |
| Kenyon, N., et al.<br>(2015).         | USA                 | CC                                                                                              | M                                    | CAS                                                                                                                                                                                             | <i>“a severe and sudden respiratory condition that, although needing aggressive and urgent treatment, has not progressed to irreversible hypoxia and cardiopulmonary arrest”.</i>                                                   |
| Werner, H. A. (2001).                 | USA                 | CC                                                                                              | C                                    | SA                                                                                                                                                                                              | <i>“the condition of a patient in progressive respiratory failure due to asthma, in whom conventional forms of therapy have failed”</i>                                                                                             |
| Nichols, D. G. (1996).                | USA                 | CC                                                                                              | C                                    | SA                                                                                                                                                                                              | <i>“acute bronchospasm that is resistant to bronchodilator therapy”</i>                                                                                                                                                             |
| Victoria, M. S., et al.<br>(1991).    | USA                 | CC                                                                                              | C                                    | SA                                                                                                                                                                                              | No definition provided                                                                                                                                                                                                              |
| Summer, W. R. (1985).                 | USA                 | R                                                                                               | m                                    | SA                                                                                                                                                                                              | <i>“an acute exacerbation of bronchial asthma, characterised by severe obstruction and not relieved with usual treatment”</i>                                                                                                       |
| Phelan, P. D. (1985).                 | USA                 | R                                                                                               | C                                    | SLTA                                                                                                                                                                                            | <i>“acute respiratory distress as a result of asthma that does not respond promptly to an adequate dose of a beta2-sympathomimetic drug or that requires such drugs more frequently than every three to four hours”.</i>            |
| Kurland, G. and A. B.<br>Leong (1985) | USA                 | R                                                                                               | C                                    | SA                                                                                                                                                                                              | <i>“acute severe wheezing that is not significantly reversed by the administration of a series of subcutaneous injections of epinephrine or terbutaline, inhaled beta-adrenergic agents, or a combination of these treatments”.</i> |

| Author(s) / year                            | Origin<br>(country) | Clinical Team<br>(Respiratory<br>(R)/ Critical<br>Care (CC)/<br>Emergency<br>Department<br>(ED) | Population<br>child (C)<br>mixed (M) | Name<br>Status Asthmaticus<br>(SA), Severe Life<br>Threatening Asthma<br>(SLTA), Near Fatal<br>Asthma (NFA)<br>Critical Asthma<br>Syndrome (CAS) or<br>subset Acute<br>Asphyxia Asthma<br>(AAA) | Definition                                                                                    |
|---------------------------------------------|---------------------|-------------------------------------------------------------------------------------------------|--------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|
| Bierman, C. W. and W.<br>E. Pierson (1974). | USA                 | R                                                                                               | C                                    | SA                                                                                                                                                                                              | <i>"Asthma unresponsive to epinephrine injections"</i>                                        |
| Siegel, S. C. and W.<br>Richards (1971).    | USA                 | CC                                                                                              | C                                    | SA                                                                                                                                                                                              | <i>"a state of severe wheezy which fails to respond to<br/>adequate doses of epinephrine"</i> |

### 3.4.4 Objective measurements

Objective measurements were included within 47 (n=47/52) of the studies. There were a mixture of cohort studies (n=18/47) which reported values for their study inclusion criteria, case reports (n=19/47) which provided actual values for children during or just before the critical attack and expert opinion (n=10/47).

The following objective measurements were found and included in Table 12:

- PaCO<sub>2</sub> - Partial pressure of carbon dioxide in arterial blood expressed in millimetre of mercury (mmHg)
- PaO<sub>2</sub> - Partial pressure of oxygen expressed in millimetre of mercury (mmHg)
- pH – specify the acidity or basicity within the blood
- SpO<sub>2</sub> - peripheral capillary oxygen saturation expressed as a percentage (%)
- Pulsus paradoxus (PP) - a fall of systolic blood pressure of >10 mmHg during the inspiratory phase.
- HR – heart rate measured as beats per minute
- RR – respiratory rate measured as breaths per minute

#### 3.4.4.1 PaCO<sub>2</sub>

Overall PaCO<sub>2</sub> was reported in 40 studies (n=40/47). PaCO<sub>2</sub> was provided in 16 (n=16/18) of the cohort studies with a range between 45mmHg and 70mmHg. None of the studies reported values in kilopascals (kPa). Within the case reports 16 (n=16/19) offered a range between 45mmHg – 140mmHg. Eight of the expert opinion manuscripts (n=8/10) offered a range between 38mmHg - >100mmHg. The mode<sup>2</sup> across all three groups (n=9/47) was a PaCO<sub>2</sub> ≥45mmHg which was provided as a value rather than a range of values.

<sup>2</sup> The mode refers to the most common actual value reported as opposed to a range of values across all of the objective measurements.



#### **3.4.4.2 PaO<sub>2</sub>**

PaO<sub>2</sub> was reported less frequently than PaCO<sub>2</sub>. Overall PaO<sub>2</sub> was reported in 14 studies (n=14/47). Within cohort studies PaO<sub>2</sub> was included on 4 occasions (n=4/18) with a range between ≤50mmHg and 60mmHg. None of the studies reported values in kilopascals (kPa). Case reports included PaO<sub>2</sub> on five (n=5/19) occasions with a vast range between ≤50mmHg – 180mmHg. Expert opinion offered PaO<sub>2</sub> values within five papers (n=5/10) with a range between ≤50mmHg and 60mmHg. The mode across all three groups (n=8/47) was a PaO<sub>2</sub> ≥60mmHg.

#### **3.4.4.3 pH**

Overall pH was reported in 17 studies (n=17/47). pH was reported within 6 cohort studies (n=6/18) with a range between ≤7.1 and ≤7.3. Case reports provided the greatest range in ten studies (n=10/19) between 6.7 and 7.35. pH was included in only one of the expert opinion pieces (n=1/10) with a value of ≤7.2. The mode across all three groups (n=7/47) was a pH of ≤7.2.

#### **3.4.4.4 SpO<sub>2</sub>**

SpO<sub>2</sub> was only reported within four studies (n=4/47). One cohort study (n=1/18) used a value of <90%. Case reports offered a range of 88% - 92% in two studies (n=2/19). Expert opinion was provided in one study (n=1/10) with a value of <92%.

#### **3.4.4.5 Pulsus paradoxus**

Pulsus paradoxus was reported on six occasions (n=6/47) within this review. It was not used within cohort studies. In the one case report it was included within (n=1/19) no value was offered. Within expert opinion it was included five times (n=5/10) with a value on >10mmHg provided by two authors (n=2/10), >20mmHg by one author (n=1/10) and no value provided in the third.

#### **3.4.4.6 HR and RR**

Values were not routinely offered for these objective measurements however tachypnoea (fast breathing) and tachycardia (fast heart rate above normal resting value) were documented in six case reports (n=6/19) and by two (n=2/10) experts without a specific heart or respiratory rate identified.

**TABLE 12: Objective measurements identified within the scoping review in chronological order.**

| Author(s) / year                     | Origin      | 1 <sup>3</sup> | 2 <sup>4</sup> | Objective measurements   |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
|--------------------------------------|-------------|----------------|----------------|--------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|------|---------------------------------------------------------------------------------------------|--|
| COHORT STUDIES                       |             |                |                | PaCO <sub>2</sub> (mmHg) |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |      | other                                                                                       |  |
|                                      |             |                |                | ≥45                      | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3 |                                                                                             |  |
| Serrano-Pariente, J., plaza V (2017) | Spain       | R              | M              | √                        |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
| Sekiya, K., et al. (2016).           | Japan       | R              | M              | √                        |     |     |     |     |     |                         |     | √   |     |      |      |      | SpO <sub>2</sub> <90%                                                                       |  |
| Serrano-Pariente, J., et al. (2015). | Spain       | R              | M              |                          | √   |     |     |     |     |                         |     |     |     |      |      | √    | hypoxaemia                                                                                  |  |
| Schutte, D., et al. (2013).          | Netherlands | CC             | C              | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      | hypercapnia<br>hypoxaemia<br>respiratory acidosis                                           |  |
| Newth, C. J. L., et al. (2012).      | USA         | CC             | C              |                          | √   |     |     |     |     |                         |     |     |     | √    |      |      | pH 7.26 (7.17-7.35)<br>PCO <sub>2</sub> 52 (38-68)mmHg<br>PaO <sub>2</sub> 109 (65-166)mmHg |  |
| Nannini, L. J., et al. (2007).       | Argentina   | R              | M              | √                        |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
| Yao, T. C., et al. (2003).           | China       | R              | C              | √                        |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
| Mitchell, I., et al. (2002).         | Canada      | R              | C              | √                        |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
| Martin, A. J., et al. (1995).        | Australia   | R              | C              |                          | √   |     |     |     |     |                         |     |     |     |      |      |      |                                                                                             |  |
| Cox, R. G., et al. (1991).           | Canada      | CC             | C              | √                        |     |     |     |     |     |                         |     |     |     |      |      | √    |                                                                                             |  |
| Zimmerman, J. E., et al. (1990).     | New Zealand | CC             | C              |                          |     |     |     | √   |     |                         |     |     |     |      |      |      |                                                                                             |  |

<sup>3</sup> 1 = Discipline, R = Respiratory, CC = Critical Care, ED = Emergency Department

<sup>4</sup> 2 = Population, C= child, M= mixed

| Author(s) / year                | Origin       | 1  | 2 | Objective measurements      |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                                                                             |                                |
|---------------------------------|--------------|----|---|-----------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|------|---------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|
| COHORT STUDIES                  |              |    |   | PaCO <sub>2</sub> (mmHg)    |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |      | Other                                                                                                                                       |                                |
|                                 |              |    |   | ≥45                         | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3 |                                                                                                                                             |                                |
| Bohn, D., et al. (1984).        | Canada       | CC | C |                             | √   |     |     |     |     |                         |     |     |     |      | √    |      | tachycardia                                                                                                                                 |                                |
| Herman, J. J., et al. (1983).   | USA          | CC | C |                             |     |     | √   |     |     |                         |     |     |     |      |      |      |                                                                                                                                             |                                |
| Shapiro, G. G., et al. (1974).  | USA          | R  | C | No values within parameters |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                                                                             | PaCO <sub>2</sub> 22-51mmHg    |
| Pierson, W. E., et al. (1974)   | USA          | R  | C |                             |     |     | √   |     |     |                         |     | √   |     |      |      |      |                                                                                                                                             |                                |
| Kampschulte, S., et al. (1973). | USA          | CC | C |                             |     |     | √   |     |     | √                       |     |     |     | √    |      |      |                                                                                                                                             |                                |
| Downes, J. J., et al. (1973).   | USA          | CC | C |                             |     | √   |     |     |     |                         |     |     |     |      |      |      |                                                                                                                                             |                                |
| Wood, D. W., et al. (1972).     | USA          | CC | C |                             |     |     |     |     | √   |                         |     |     |     |      | √    |      |                                                                                                                                             |                                |
| CASE REVIEWS                    |              |    |   |                             |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                                                                             |                                |
| Alzeer, A. H., et al. (2015).   | Saudi Arabia | CC | C |                             |     |     |     |     |     |                         |     | √   |     |      |      |      | BP 120/70 mmHg<br>HR110/min<br>RR 42/min<br>oxygen saturation was 92% on FiO <sub>2</sub> of 6L/min.<br>pH 7.35<br>PCO <sub>2</sub> 37 mmHg |                                |
| Martchek, M. A., et al. (2015). | USA          | ED | C | No available data           |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                                                                             | HR 122 bpm<br>BP 208/126 mm Hg |

| Author(s) / year                      | Origin  | 1  | 2 | Objective measurements   |     |     |     |     |     |                         |     |     |     |      |      |                                                                                                                                                          |       |
|---------------------------------------|---------|----|---|--------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|----------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| CASE REVIEWS                          |         |    |   | PaCO <sub>2</sub> (mmHg) |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |                                                                                                                                                          | Other |
|                                       |         |    |   | ≥45                      | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3                                                                                                                                                     |       |
| Carrie, S. and T. A. Anderson (2015). | Canada  | CC | C |                          |     |     |     |     |     |                         |     |     |     | √    |      | pulsus paradoxus<br>PaCO <sub>2</sub> 90–100 mmHg<br>hypotension                                                                                         |       |
| Quizon, A. and E. Forno (2014).       | USA     | R  | C | √                        |     |     |     |     |     |                         |     |     |     |      |      | tachypnoea<br>tachycardia<br>SpO <sub>2</sub> 88%<br>pH 7.35<br>PEFR < 40%<br>predicted/best                                                             |       |
| Kaelin, M. and R. L. Morton (2002).   | USA     | CC | C |                          |     |     |     |     |     |                         |     | √   |     |      |      | pH6.97<br>PaCO <sub>2</sub> 83mmHg                                                                                                                       |       |
| Siddiqi, A. and V. Bandi (1999).      | USA     | CC | C |                          | √   |     |     |     |     |                         |     |     |     |      |      | Case 2<br>pH6.7<br>PCO <sub>2</sub> 138mmHg<br>PO <sub>2</sub> 180mmHg                                                                                   |       |
| Niggemann, B. and U. Wahn (1992).     | Germany | CC | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      | hypoxaemia                                                                                                                                               |       |
| Otte, R. W. and P. Fireman (1991).    | USA     | CC | C |                          |     |     | √   |     |     |                         |     |     |     |      | √    | PaO2 110mmHg                                                                                                                                             |       |
| Gluck, E. H., et al. (1990).          | USA     | CC | M |                          | √   |     |     |     |     |                         |     | √   |     | √    |      |                                                                                                                                                          |       |
| Levin, N. and J. B. Dillon (1972)     | USA     | CC | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      | 4 case studies<br>Hypertension<br>Tachycardic<br>Tachypnoeic<br>PaCO <sub>2</sub> 55mmHg – 103mmHg<br>PaO <sub>2</sub> 58mmHg - 68mmHg<br>pH 7.08 - 7.16 |       |

| Author(s) / year                       | Origin | 1                 | 2 | Objective measurements   |     |     |     |     |     |                         |     |     |     |      |      |                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                       |  |
|----------------------------------------|--------|-------------------|---|--------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| CASE REVIEWS                           |        |                   |   | PaCO <sub>2</sub> (mmHg) |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |                                                                                                                                                                                                                                                                                                                                                                                                        | Other                                                                                                                                                 |  |
|                                        |        |                   |   | ≥45                      | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3                                                                                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                       |  |
| Rhine, E. J. and J. K. Rosales (1970). | Canada | CC                | C |                          |     |     |     | √   |     |                         |     |     |     |      | √    |                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                       |  |
| Wood, D. W., et al. (1968).            | USA    | CC                | C |                          |     |     |     | √   |     |                         |     |     |     |      |      |                                                                                                                                                                                                                                                                                                                                                                                                        |                                                                                                                                                       |  |
| Downes, J. J., et al. (1968).          | USA    | CC                | C |                          |     |     |     |     |     |                         |     |     |     | √    |      |                                                                                                                                                                                                                                                                                                                                                                                                        | PaCO <sub>2</sub> >65mmHG severe hypercapnia<br>PaCO <sub>2</sub> 40 -65mmHg mild to moderate hypercapnia<br>PaCO <sub>2</sub> <40mmHg no hypercapnia |  |
| Strauss, J., et al. (1966).            | USA    | No available data | C |                          |     | √   |     |     |     |                         |     |     |     |      |      | √                                                                                                                                                                                                                                                                                                                                                                                                      |                                                                                                                                                       |  |
| Misuraca, L. (1966).                   | USA    | CC                | M |                          |     |     | √   |     |     |                         |     |     |     |      |      |                                                                                                                                                                                                                                                                                                                                                                                                        | Decreased PaO <sub>2</sub><br>Fall in pH                                                                                                              |  |
| Downes, J. J., et al. (1966).          | USA    | CC                | C |                          |     |     |     |     |     |                         |     |     |     |      | √    |                                                                                                                                                                                                                                                                                                                                                                                                        | PaCO <sub>2</sub> 86mmHg (range 65 – 168)                                                                                                             |  |
| Beam, L. R., et al. (1965              | USA    | CC                | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      | Rising PCO <sub>2</sub><br>Falling PO <sub>2</sub><br>Tachycardia<br>Case 1 <ul style="list-style-type: none"><li>PaCO<sub>2</sub> 45-70 mmHg</li><li>pH 7.22 – 7.32</li></ul> Case 2 <ul style="list-style-type: none"><li>PaCO<sub>2</sub> 46.3-62mmHg,</li><li>pH 7.16 – 7.51</li></ul> Case 3 <ul style="list-style-type: none"><li>PaCO<sub>2</sub> 49 - 112 mmHg</li><li>pH 7.28 – 7.5</li></ul> |                                                                                                                                                       |  |

| Author(s) / year             | Origin  | 1         | 2 | Objective measurements   |     |     |     |     |     |                         |     |     |     |      |      |      |            |                                                                                                                                                                                                          |
|------------------------------|---------|-----------|---|--------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|------|------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| CASE REVIEWS                 |         |           |   | PaCO <sub>2</sub> (mmHg) |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |      | Other      |                                                                                                                                                                                                          |
|                              |         |           |   | ≥45                      | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3 |            |                                                                                                                                                                                                          |
| Bukantz, S. C. (1963).       | USA     | R         | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      |            | Case 1 <ul style="list-style-type: none"><li>cap PCO<sub>2</sub> 61mmHg and 140mmHg</li><li>cap pH 6.86 – 6.96</li><li>Case 2</li><li>cap PCO<sub>2</sub> 140mmHg and 94mmHg</li><li>normal pH</li></ul> |
| McNicholl, B. 1960           | Ireland | Not known | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      |            | Tachypnoea<br>Tachycardia<br>Increased BP                                                                                                                                                                |
| EXPERT OPINION               |         |           |   |                          |     |     |     |     |     |                         |     |     |     |      |      |      |            |                                                                                                                                                                                                          |
| Shein, S. L., et al. (2016). | USA     | CC        | C | √                        |     |     |     |     |     |                         |     |     |     |      |      |      | tachypnoea |                                                                                                                                                                                                          |
| Kenyon, N., et al. (2015).   | USA     | CC        | M | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      |            | Hypoxemia                                                                                                                                                                                                |
| Werner, H. A. (2001).        | USA     | CC        | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      |            | Decrease in pH<br>Hypoxaemia<br>Pulsus paradoxus > 10mmHg                                                                                                                                                |
| Nichols, D. G. (1996).       | USA     | CC        | C | No available data        |     |     |     |     |     |                         |     |     |     |      |      |      |            | Pulsus paradoxus > 10mmHg<br>PaCO <sub>2</sub> >42mmHg<br>SpO <sub>2</sub> <92%<br>PEFR <40% predicted<br>In AAA <ul style="list-style-type: none"><li>PaCO<sub>2</sub> &gt; 100mmHg</li></ul>           |

| Author(s) / year                         | Origin | 1  | 2 | Objective measurements   |     |     |     |     |     |                         |     |     |     |      |      |      |                                                                                 |
|------------------------------------------|--------|----|---|--------------------------|-----|-----|-----|-----|-----|-------------------------|-----|-----|-----|------|------|------|---------------------------------------------------------------------------------|
| EXPERT OPINION                           |        |    |   | PaCO <sub>2</sub> (mmHg) |     |     |     |     |     | PaO <sub>2</sub> (mmHg) |     |     |     | pH   |      |      | Other                                                                           |
|                                          |        |    |   | ≥45                      | ≥50 | ≥55 | ≥60 | ≥65 | ≥70 | ≤50                     | ≤55 | ≤60 | ≤65 | ≤7.1 | ≤7.2 | ≤7.3 |                                                                                 |
| Victoria, M. S., et al. (1991).          | USA    | CC | C | √                        |     |     |     |     |     |                         | √   |     |     |      |      |      |                                                                                 |
| Summer, W. R. (1985).                    | USA    | R  | m |                          |     |     |     |     |     | √                       |     |     |     |      |      |      | Pulsus paradoxus<br>PaCO <sub>2</sub> 38 - >100mmHg                             |
| Phelan, P. D. (1985).                    | USA    | R  | C |                          |     |     | √   |     |     |                         |     |     |     |      |      |      | Pulsus paradoxus<br>>20mmHg<br>Hypoxia                                          |
| Kurland, G. and A. B. Leong (1985)       | USA    | R  | C |                          |     |     |     | √   |     |                         |     | √   |     |      |      |      | Hypoxaemia<br>Tachypnoea<br>Increased lactate<br>Falling pH<br>Pulsus paradoxus |
| Bierman, C. W. and W. E. Pierson (1974). | USA    | R  | C |                          |     |     |     | √   |     |                         |     | √   |     |      |      |      | Falling pH                                                                      |
| Siegel, S. C. and W. Richards (1971).    | USA    | CC | C |                          |     |     |     | √   |     |                         |     | √   |     |      | √    |      |                                                                                 |



### **3.4.5 Clinical features**

The clinical features identified within the scoping review are presented in table 13. Terms were aligned for consistency e.g. obtundation was reported as altered consciousness. Clinical features were included within 45 (n=45/52) of the studies. There were a mixture of cohort studies (n=18/45), case reports (n=19/45) and expert opinion (n=8/45). A total of 20 clinical features were identified with five features reported most frequently:

- altered consciousness
- mechanical ventilation
- accessory muscles use
- cyanosis
- silent chest

#### **3.4.5.1 Altered consciousness**

Altered consciousness was the most commonly reported clinical feature across this review (n=28/45). Terms such as impaired, disturbance, obtundation and altered were all used to describe levels of consciousness with altered being the most popular term to align to. Cohort studies (n=11/18), case reports (n=12/19) and expert opinion (n=5/8) describe altered consciousness as a key feature however none reported the use of a scoring tool such as AVPU (Alert, verbal, pain, unresponsive) or the Glasgow Coma Scale (GCS) to indicate how altered the conscious level was.

#### **3.4.5.2 Mechanical ventilation**

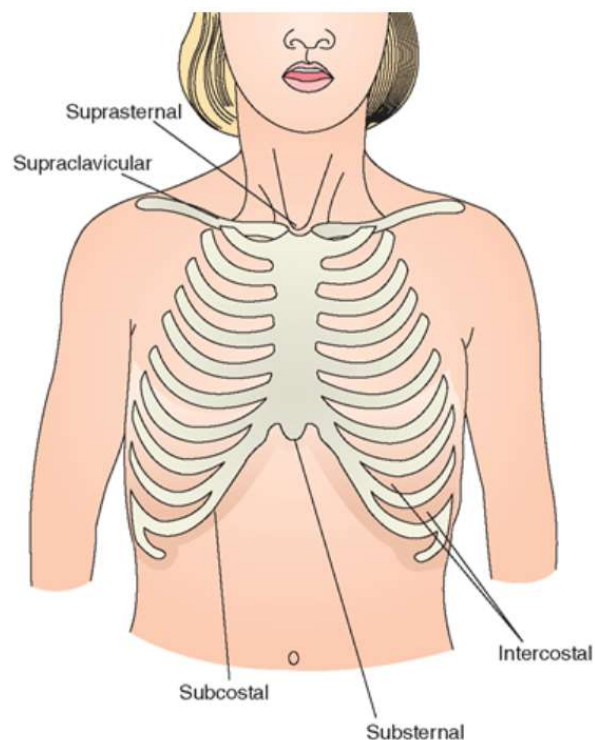
Mechanical ventilation was the second most popular feature reported by authors within this review (n=28/45). Cohort studies (n=12/18), case reports (n=11/19) and expert opinion (n=2/8) all identified patients who required ventilation due to their significant deterioration and lack of response to treatment as a key characteristic.

#### 3.4.5.3 Accessory muscles use

Excessive accessory muscle use was identified as a key feature in this review (n=19/45) with terms such as recession or retractions used as prefixes. In addition to those accessory muscles featuring in Figure 8, sternocleidomastoid retraction was also noted. Cohort studies (n=5/18), case reports (n=9/19) and expert opinion (n=5/8) identified this as a key sign of respiratory distress and measure of deterioration.

**FIGURE 8: POSITIONS OF ACCESSORY MUSCLES.**

Available from <https://kidnurse.org/respiratory-distress/>



#### 3.4.5.4 Cyanosis

Cyanosis (blue skin or lips) is divided into two main types: central (e.g. lips or tongue) and peripheral (e.g. fingers or toes) and was identified as an important sign in this review (n=18/45) but the type of cyanosis was not specified and is presumed central. Cohort studies (n=4/18), case reports (n=11/19) and expert opinion (n=3/8) documented cyanosis as a sign of a critical asthma attack which was present in room air and persisted despite high flow oxygen.

#### **3.4.5.5 Silent chest**

During an asthma attack, wheeze occurs due to the underlying pathophysiology of airway inflammation which causes restricted airflow through partially constricted small and large airways. The characteristics of wheeze may change with increasing obstruction, while in severe life threatening attacks there may be insufficient airflow to generate any wheeze, resulting in a “silent chest” (Swarnkar et al., 2021) . A silent chest was identified as a key characteristic in this review (n=16/45), included in cohort studies (n=2/18), case reports (n= 9/19) and by experts (n=5/8). Severe wheeze was extracted from the data less frequently (n=10/45).

**TABLE 13: CLINICAL FEATURES IDENTIFIED WITHIN THE SCOPING REVIEW.**

| Author(s) / year                     | Origin      | 1  | 2 | Clinical features  |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
|--------------------------------------|-------------|----|---|--------------------|-----------------|-------------------------|-----------------------|----------|--------|---------|------------------|--------------|-----------------------|------------------|--------|----------|-----------------|------|-----------------|---------------------|--------------------|------------------------|------------------------|
| COHORT STUDIES                       |             |    |   |                    |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
|                                      |             |    |   | Inability to speak | Severe wheezing | Accessory muscle use ++ | Failure to respond to | Dyspnoea | Sweaty | Fatigue | Poor muscle tone | Silent chest | Altered consciousness | Agonal breathing | Apnoea | Cyanosis | Sudden collapse | Coma | Hypoxic seizure | Cardiac arrhythmias | Respiratory arrest | Cardiopulmonary arrest | Mechanical ventilation |
| Serrano-Pariente J., plaza V (2017). | Spain       | R  | M | ✓                  |                 |                         |                       |          |        |         |                  |              | ✓                     |                  |        |          |                 |      |                 |                     |                    | ✓                      | ✓                      |
| Sekiya, K., et al. (2016).           | Japan       | R  | M |                    |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        | ✓                      |
| Serrano-Pariente J., et al. (2015).  | Spain       | R  | M |                    |                 |                         |                       |          |        |         |                  |              | ✓                     |                  |        |          |                 |      |                 | ✓                   |                    |                        | ✓                      |
| Schutte, D., et al. (2013).          | Netherlands | CC | C |                    |                 |                         |                       |          |        |         |                  |              | ✓                     |                  |        |          |                 |      |                 |                     |                    |                        | ✓                      |
| Newth, C. J. L., et al. (2012).      | USA         | CC | C |                    |                 |                         |                       |          |        |         |                  |              | ✓                     |                  |        |          |                 |      |                 |                     |                    | ✓                      | ✓                      |
| Nannini, L. J., et al. (2007).       | Argentina   | R  | M |                    |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 | ✓                   |                    |                        | ✓                      |
| Mitchell, I., et al. (2002).         | Canada      | R  | C |                    |                 |                         |                       |          |        |         |                  |              | ✓                     |                  |        |          |                 |      |                 |                     |                    | ✓                      | ✓                      |
| Schmitz, T., et al. (2000).          | Germany     | R  | C |                    |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        | ✓                      |
| Martin, A. J., et al. (1995).        | Australia   | R  | C | ✓                  |                 | ✓                       |                       |          |        |         |                  |              | ✓                     |                  |        |          | ✓               |      |                 |                     |                    |                        |                        |
| Richards, G. N., et al. (1993).      | New Zealand | R  | M |                    |                 |                         |                       |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    | ✓                      | ✓                      |
| Cox, R. G., et al. (1991).           | Canada      | CC | C |                    | ✓               |                         |                       |          |        | ✓       |                  |              | ✓                     |                  | ✓      | ✓        |                 |      |                 |                     |                    |                        | ✓                      |
| Zimmerman, J. E., et al. (1990).     | New Zealand | CC | C |                    |                 |                         | ✓                     |          |        |         |                  |              | ✓                     |                  | ✓      | ✓        |                 |      | ✓               |                     |                    | ✓                      |                        |
| Bohn, D., et al. (1984).             | Canada      | CC | C |                    | ✓               |                         |                       |          |        | ✓       |                  |              |                       |                  | ✓      |          |                 |      |                 | ✓                   |                    |                        | ✓                      |
| Herman, J. J., et al. (1983).        | USA         | CC | C |                    | ✓               | ✓                       |                       |          |        |         |                  | ✓            | ✓                     |                  |        |          |                 |      |                 |                     |                    |                        |                        |

| Author(s) / year                       | Origin       | 1  | 2 | Inability to speak | Severe wheezing | Accessory muscle use ++ | Failure to respond to treatment | Dyspnoea | Sweaty | Fatigue | Poor muscle tone | Silent chest | Altered consciousness | Agonal breathing | Apnoea | Cyanosis | Sudden collapse | Coma | Hypoxic seizure | Cardiac arrhythmias | Respiratory arrest | Cardiopulmonary arrest | Mechanical ventilation |
|----------------------------------------|--------------|----|---|--------------------|-----------------|-------------------------|---------------------------------|----------|--------|---------|------------------|--------------|-----------------------|------------------|--------|----------|-----------------|------|-----------------|---------------------|--------------------|------------------------|------------------------|
| Pierson, W. E., et al. (1974)          | USA          | R  | C |                    |                 | √                       |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Kampschulte, S., et al. (1973).        | USA          | CC | C |                    |                 | √                       |                                 |          |        |         |                  |              | √                     |                  |        | √        |                 | √    |                 |                     |                    |                        | √                      |
| Downes, J. J., et al. (1973).          | USA          | CC | C |                    | √               |                         |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Wood, D. W., et al. (1972).            | USA          | CC | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  |        | √        |                 |      |                 |                     |                    |                        |                        |
| <b>CASE REPORTS</b>                    |              |    |   |                    |                 |                         |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Alzeer, A. H., et al. (2015).          | Saudi Arabia | CC |   |                    | √               | √                       |                                 |          | √      |         |                  | √            |                       |                  |        |          |                 |      |                 |                     |                    |                        | √                      |
| Martchek, M. A., et al. (2015).        | USA          | ED | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     | √                |        |          | √               |      |                 |                     |                    |                        |                        |
| Carrie, S. and T. A. Anderson (2015).  | Canada       | CC | C | √                  |                 |                         |                                 |          | √      |         |                  | √            | √                     |                  |        | √        |                 |      |                 | √                   |                    |                        | √                      |
| Quizon, A. and E. Forno (2014).        | USA          | R  | C | √                  |                 |                         |                                 | √        |        |         |                  | √            | √                     |                  |        |          |                 |      |                 |                     |                    |                        | √                      |
| Maffei, F. A., et al. (2004).          | USA          | CC | C |                    |                 |                         |                                 |          |        |         |                  | √            | √                     |                  | √      | √        |                 |      |                 |                     | √                  |                        | √                      |
| Kaelin, M. and R. L. Morton (2002).    | USA          | CC | C |                    |                 |                         |                                 | √        |        |         |                  |              | √                     |                  |        | √        |                 |      |                 |                     |                    |                        | √                      |
| Siddiqi, A. and V. Bandi (1999).       | USA          | CC | C |                    |                 |                         | √                               |          |        |         |                  |              | √                     | √                |        |          |                 |      |                 | √                   |                    |                        |                        |
| Niggemann, B. and U. Wahn (1992).      | Germany      | CC | C |                    |                 |                         |                                 | √        |        |         |                  |              | √                     |                  |        | √        |                 |      |                 |                     |                    |                        |                        |
| Otte, R. W. and P. Fireman (1991).     | USA          | CC | C |                    | √               |                         | √                               | √        |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Levin, N. and J. B. Dillon (1972)      | USA          | CC | C |                    | √               |                         | √                               | √        |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Rhine, E. J. and J. K. Rosales (1970). | Canada       | CC | C |                    |                 | √                       |                                 |          |        |         | √                | √            | √                     |                  |        | √        |                 |      |                 |                     |                    |                        | √                      |
| Wood, D. W., et al. (1968).            | USA          | CC | C |                    |                 | √                       |                                 |          |        |         | √                | √            | √                     |                  |        | √        |                 |      |                 |                     |                    |                        | √                      |
| Downes, J. J., et al. (1968).          | USA          | CC | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  | √      | √        |                 | √    |                 |                     | √                  |                        | √                      |
| Strauss, J., et al. (1966).            | USA          |    | C |                    |                 | √                       |                                 |          |        |         |                  |              |                       |                  |        | √        |                 |      |                 |                     |                    |                        |                        |

| Author(s) / year                      | Origin  | 1  | 2 | Inability to speak | Severe wheezing | Accessory muscle use ++ | Failure to respond to treatment | Dyspnoea | Sweaty | Fatigue | Poor muscle tone | Silent chest | Altered consciousness | Agonal breathing | Apnoea | Cyanosis | Sudden collapse | Coma | Hypoxic seizure | Cardiac arrhythmias | Respiratory arrest | Cardiopulmonary arrest | Mechanical ventilation |
|---------------------------------------|---------|----|---|--------------------|-----------------|-------------------------|---------------------------------|----------|--------|---------|------------------|--------------|-----------------------|------------------|--------|----------|-----------------|------|-----------------|---------------------|--------------------|------------------------|------------------------|
| Misuraca, L. (1966).                  | USA     | CC | M |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  |        |          | √               |      |                 |                     |                    |                        | √                      |
| Downes, J. J., et al. (1966).         | USA     | CC | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  |        | √        |                 |      |                 |                     |                    |                        | √                      |
| Beam, L. R., et al. (1965)            | USA     | CC | C |                    |                 | √                       | √                               | √        |        | √       |                  |              |                       |                  |        | √        |                 |      |                 |                     |                    |                        | √                      |
| Bukantz, S. C. (1963).                | USA     | R  | C |                    |                 |                         |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    | √                      |                        |
| McNicholl, B. 1960                    | Ireland |    | C |                    |                 | √                       |                                 |          |        |         |                  |              |                       |                  |        | √        |                 |      |                 |                     |                    |                        |                        |
| <b>EXPERT OPINION</b>                 |         |    |   |                    |                 |                         |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Shein, S. L., et al. (2016).          | USA     | CC | C |                    | √               |                         |                                 | √        |        | √       |                  |              | √                     |                  |        |          |                 |      |                 |                     |                    |                        | √                      |
| Kenyon, N., et al. (2015).            | USA     | CC | M |                    |                 |                         | √                               | √        |        | √       |                  |              |                       |                  |        |          | √               |      |                 |                     | √                  |                        |                        |
| Werner, H. A. (2001).                 | USA     | CC | C |                    | √               | √                       |                                 | √        |        |         |                  | √            |                       |                  |        |          |                 |      |                 |                     |                    | √                      | √                      |
| Nichols, D. G. (1996).                | USA     | CC | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  |        |          |                 |      |                 |                     |                    |                        |                        |
| Victoria, M. S., et al. (1991).       | USA     | CC | C |                    |                 | √                       |                                 |          |        |         |                  | √            | √                     |                  |        | √        |                 |      |                 | √                   | √                  |                        |                        |
| Summer, W. R. (1985).                 | USA     | R  | m |                    | √               | √                       |                                 | √        |        |         |                  | √            | √                     |                  |        | √        |                 |      |                 | √                   |                    |                        |                        |
| Kurland, G. and A. B. Leong (1985)    | USA     | R  | C |                    |                 |                         |                                 |          |        |         |                  |              |                       |                  |        |          |                 |      |                 | √                   |                    |                        |                        |
| Siegel, S. C. and W. Richards (1971). | USA     | CC | C |                    |                 | √                       |                                 |          |        |         | √                | √            | √                     |                  |        | √        |                 |      |                 |                     |                    |                        |                        |

### 3.4.6 Parent/ carer/ patient perspective

An extensive literature search yielded limited data on the parent/ patient perspective of a critical asthma attack (n=2/45) and these were presented as case reports (n=2/19) in table 14. These were all written as an account from a clinician's perspective. In one report a sense of awareness of the severity of the attack was documented prior to loss of consciousness and cyanosis. In the second report, the boy coming into the garden crying may have been indicative of air hunger and the feeling of not being able to breathe indoors, this was associated with collapse.

**TABLE 14: PARENT AND PATIENT PERSPECTIVE OF A CRITICAL ASTHMA ATTACK.**

| Author(s) / year                    | Origin (country) | Study design<br>Cohort (C)<br>Case Study (CR)<br>Expert Opinion (EO) | Clinical Team<br>R/ CC/ ED/ | Population<br>Child (C)<br>mixed (M) | Parent/ carer/ patient perspective                                                        |
|-------------------------------------|------------------|----------------------------------------------------------------------|-----------------------------|--------------------------------------|-------------------------------------------------------------------------------------------|
| <b>CASE REPORTS</b>                 |                  |                                                                      |                             |                                      |                                                                                           |
| Kaelin, M. and R. L. Morton (2002). | USA              | CR                                                                   | CC                          | C                                    | 12 year old girl "I feel like I am going to die," lost consciousness, and became cyanotic |
| Niggemann, B. and U. Wahn (1992).   | Germany          | CR                                                                   | CC                          | C                                    | 14 year old boy went running into the garden crying for help then collapsed               |

### 3.4.7 Other key features

Two additional features were extracted from the data which were felt to be relevant for inclusion in this review (n=2/45) and are presented in table 15. The concept of becoming a poor perceiver of asthma symptoms after experiencing a severe life-threatening asthma attack places significant risk to the person with future attacks especially when making decisions on the appropriate time for medical review. This was included in the discussion of one cohort study (n=1/18). The provision of an adrenaline pen for future management of severe attacks has not been widely accepted within clinical practice however was an interesting concept for inclusion in this review. This was a recommendation for practice within one case report (n=1/18).

**TABLE 15: OTHER KEY FEATURES OF A CRITICAL ASTHMA ATTACK.**

| <b>Author(s) /<br/>year</b>       | <b>Origin</b> | <b>Study<br/>design</b><br>Cohort (C)<br>Case Study<br>(CR)<br>Expert<br>Opinion<br>(EO) | <b>Clinical<br/>Team</b><br>R/ CC/<br>ED/ | <b>Population</b><br>Child (C)<br>mixed (M) | <b>Other key features</b>                                                          |
|-----------------------------------|---------------|------------------------------------------------------------------------------------------|-------------------------------------------|---------------------------------------------|------------------------------------------------------------------------------------|
| <b>COHORT STUDY</b>               |               |                                                                                          |                                           |                                             |                                                                                    |
| Julius, S. M., et al. (2002).     | USA           | C                                                                                        | R                                         | C                                           | Those with previous severe life threatening asthma are poor perceivers of symptoms |
| <b>CASE REPORT</b>                |               |                                                                                          |                                           |                                             |                                                                                    |
| Niggemann, B. and U. Wahn (1992). | Germany       | CR                                                                                       | CC                                        | C                                           | Patients should be provided with an epipen if they experience this type of attack  |

### 3.5 Discussion

This scoping review has presented data in relation to a critical asthma attack found in cohort studies, case reports and expert opinion from a predominantly paediatric viewpoint of clinicians in emergency department, respiratory and critical care medicine. There were no studies identified as randomised controlled studies which may be reflective of the difficulty in designing trials for uncommon, acutely presenting severe conditions. In the past seven decades the name and definition used to describe a critical asthma attack has undergone several iterations. Status asthmaticus, despite being recognised as an outdated term (Louie et al., 2012), remains the only term used to describe this event in medical coding worldwide (World Health Organization, 2018) and may explain the reluctance of authors to use alternatives. Status asthmaticus refers to a broad range of attack severity and the seriousness of a critical attack may be under appreciated if grouped under a single term. Grouping attacks under a single term also prevents data being collected which could provide an incidence of critical asthma attacks in the population. There is no explanation of how the other names identified in this review, Severe Life Threatening Asthma (SLTA), Near-Fatal Asthma (NFA) and Critical Asthma Syndrome (CAS), came to be used in clinical practice. Authors do not explain the rationale for the term



used within their studies with the exception of CAS which is explained as an umbrella term (Kenyon et al., 2015). This apparent lack of consensus on the name for the event was seen across the medical disciplines, both within the same country and internationally. Most of the studies identified were single reports (from an author or group of authors), however for the two studies by Serrano-Pariente (NFA) and three studies from Downes and Wood (SA), the name used was consistent across their studies (Serrano-Pariente and Plaza, 2017, Serrano-Pariente et al., 2015, Downes et al., 1973, Downes et al., 1968, Wood et al., 1972).

Definitions used to describe the attack were highly variable, with acknowledgement from some authors that there was no consensus definition of a critical attack (Phelan, 1985, Summer, 1985, Mitchell et al., 2002). An ability to make comparison across studies will remain difficult unless core clinical outcomes and parameters are agreed (e.g.  $\text{PaCO}_2 \geq 45\text{mmHg}$  or mechanical ventilation). Although definitions vary one of the key features included in 15 of the studies was failing to respond to emergency treatment i.e. bronchodilators and adrenaline. This is important as clinicians will need to use their clinical judgement and expertise treating an attack and explore the use of other treatments (e.g. anaesthetic gases) which falls out with guidance provided in asthma guidelines worldwide (Schutte et al., 2013, Carrie and Anderson, 2015). This also demonstrates that this type of attack extends beyond those identified in current global guidelines which tend to focus primarily on moderate to severe attacks with less emphasis on critical asthma attacks.

Across this review seven objective measurements were identified.  $\text{PaCO}_2$  and pH were the two measurements most consistently reported. They were also included in a small proportion of definitions ( $n=6/52$ ) with a  $\text{PaCO}_2 \geq 45\text{mmHg}$  most commonly reported. Across the cohort studies, case reports and expert opinion, there were a range of values offered as an indicator of deteriorating asthma and respiratory failure, demonstrating a lack of agreement across identified studies.

There were twenty clinical features identified across this review. Five features were consistently identified most frequently (conscious level, mechanical ventilation, accessory muscle use, cyanosis and silent chest).

Conscious levels can be assessed using recognised scoring tools such as AVPU (Alert, Verbal, Pain, Unresponsive) which is a quick and simple way of measuring conscious level and does not require any formal training (Romanelli and Farrell, 2021). The Glasgow Coma Scale (GCS) closely correlates to AVPU with a scale ranging from 15 (Alert), 12- 13 (Verbal), 5-6 (Pain) and 3 (unresponsive) (McNarry and Goldhill, 2004). Across this review there was an absence of scoring tools utilised with a preference to refer to 'altered' or 'disturbed' consciousness. Future studies could explore the use of scoring tools, or focus on the use of AVPU. The use of AVPU could be taught to parents and incorporated into the emergency zone within an asthma plan for deteriorating asthma. Any score below A (Alert) could be used as a prompt to seek urgent medical review.

Mechanical ventilation was most commonly identified as an outcome in management of a critical asthma attack however this comes with its own associated risk factors. The actual process of intubation itself can cause more bronchoconstriction, worsening airway obstruction and increasing PaCO<sub>2</sub>. Outcomes for patients are better if the intubation is elective rather than as a result of cardiopulmonary arrest (Smyth, 1998). Ultimately the decision on when to proceed to intubation and ventilation remains a clinical judgement rather than being prescriptive (Shein et al., 2016). Although the threshold for intubation varies across and within different intensive care, particularly since the introduction of non-invasive respiratory support, it remains a valuable indicator of severity.

Accessory muscle use was reported most frequently in case reports. In clinical trials the use of a respiratory scoring tools are often used to assess the severity of an asthma attack. The Pediatric Respiratory Assessment Measure (PRAM) is the most

common tool and contains five signs which are scored: suprasternal retractions, scalene muscle retraction, air entry, wheezing and O<sub>2</sub> saturation (Ducharme et al., 2008). The presence of suprasternal retraction (when the skin in the middle of the neck sucks in/ tracheal tug) and scalene muscle retraction (muscles around the neck) are indicators of severe airway obstruction. Cyanosis was another key feature recognised within the review and found most commonly in case reports when authors described the clinical state of a child or young person. Although the type of cyanosis was not specified in the studies, central cyanosis would be a rare but serious clinical sign in an asthma attack. It is also important to note that clinical cyanosis is difficult to identify below a corresponding SpO<sub>2</sub> of <85%. Oxygen saturation measures how much haemoglobin is currently bound to oxygen compared to how much haemoglobin remains unbound (Hafen and Sharma, 2020). A pulse oximeter (machine used to measure oxygen saturation) measures light wavelengths to determine the ratio of the current levels of oxygenated haemoglobin to deoxygenated haemoglobin. As the PaO<sub>2</sub> decreases, the percentage of saturated haemoglobin also decreases which reduces the reliability of a saturation monitor below <85% (Fouzas et al., 2011). The difficulties with recording an accurate SpO<sub>2</sub> may also explain why SpO<sub>2</sub> was reported in only four studies. It is difficult to explain the rationale for this, however a blood gas can provide a PaO<sub>2</sub>, which may be more helpful when considering intubation. Teaching parents how to recognise accessory muscle use and the significance of colour change as part of their asthma plan could prove beneficial when making a decision on when to seek medical urgent medical review. There are two learning points for clinicians. Firstly, it would be important to expose the chest during an examination, as recommended by the Resuscitation Council UK ABCDE (airway, breathing, circulation, disability, exposure) approach to assessment of a sick child (Resuscitation Council UK, 2021). Children can be difficult to assess with layers of

clothing on and signs of accessory muscle use could be missed in a clinical examination, if they are not removed. Although this should be manageable for those working in a clinical setting, this may prove challenging for paramedics. They may encounter obstacles such as poor lighting, low temperature or spectators if called to respond to an attack in a public space. Secondly, measuring SpO<sub>2</sub> with the correct probe is vital. A recent patient safety alert, produced by NHS (National Health Service) Improvement, highlighted that if an oximeter probe intended for an adult is attached to a baby or a child (or vice versa), it can produce a reading up to 50% lower or 30% higher than the real value (NHS Improvement, 2018).

A silent chest is a recognised clinical feature of a life threatening asthma attack in asthma guidelines (BTS/SIGN 2019, GINA 2020). Chest auscultation is a clinical skill and there is a risk that an inexperienced clinician could confuse the absence of wheeze as reassurance rather than risk (Proctor and Rickards, 2020). This highlights that a child in respiratory distress without wheeze should be key learning point for clinicians.

### **3.6 Strengths and limitations**

This review captured data relating to children, young people and young adults and may have omitted some features which could have been extracted from adult data especially when exploring the patient voice. From the adult papers, which were excluded, the mean age of participants in the studies were >45 years. No qualitative studies were identified. Within the quantitative studies, the participants would most probably have co-morbidities such as chronic obstructive pulmonary disease or obesity. The co-morbidities could add additional risk of deterioration in terms of objective measurements such as a rising PaCO<sub>2</sub> if high flow oxygen was provided during an attack to a patient with asthma / chronic obstructive pulmonary disease overlap (Attaway et al., 2021). The purpose of this review however was to focus on the

younger population and this has been achieved. The search strategy did not include a particular community or clinical setting which was intentional. The broad search identified hospital studies only. The lack of studies or case studies published in relation to a critical asthma attack occurring in a primary care setting or by a paramedic may be indicative of how rare this type of attack is. It could however be attributed to database selection, exclusion of the grey literature from the search or the exclusion of studies published in a language other than English. It would be an important experience for clinicians to share if witnessed in the community. Clinicians could reflect upon this event to consider how this type of attack could be managed in this environment if encountered in the future.

There has been some debate as to whether a quality assessment is required within a scoping review and this is often acknowledged as a limitation (Pham et al., 2014). A quality assessment was not conducted in this study as it is not a priority in scoping reviews or part of the scoping review methodology (Arksey and O'Malley, 2005, Levac et al., 2010). This scoping review included a broad range of literature providing a more complete overview of all the research activity related to a critical asthma attack according to the search strategy. It would have been challenging assessing quality among the large volume of literature that was included in this study however this could have been managed by placing a limit on the timeframe used within the search strategy. Limiting the time frame would however have excluded some of the names used to describe the critical attack.

The data extraction was primarily conducted by one reviewer and may have benefited from the added rigour of two reviewers conducting full text analysis. All papers, extraction tables and findings were discussed regularly at supervision meetings which would meet the requirements of a scoping review process.

### **3.7 Conclusion**

The scoping review highlighted the lack of studies which explored the parents or patients perspective of a critical asthma attack. The two studies included reported the patient experience from the clinician's perspective and highlight the gap in current research. All of the studies were clinically led and assumed observations using diagnostic tools likely to be unavailable to either parent or patient at the time of attack onset. The identification of precursors, or a set of guidelines that could be easily integrated into an asthma plan could assist in early identification of possible critical asthma attacks, leading to the parent or patient seeking urgent medical help. The absence of the patient voice reinforces the need to acknowledge this as a research priority.

There is lack of consistency in name, definition, clinical signs and objective measurements which define a critical asthma attack even within practicing clinicians. This identifies a gap in knowledge and a need for further research in order to achieve consensus on a name and definition for this event by engaging with key stakeholders in the fields of ED, Critical Care and Respiratory medicine. Agreement in both, would enable the frequency of defined events to be measured, against which future interventions could be trialled to reduce attacks and asthma deaths.

### **3.8 Summary and next steps**

In this chapter I have reported on the results of a scoping review. The results from this chapter will help inform the round one questionnaire of the eDelphi (see section 5.8). In the next chapter I will present the aims, methods and results of a review which explored global asthma guidelines. This was to augment the scoping review and ensure that eDelphi round one was presented with an appropriate level of scrutiny of both guidelines and published evidence.

## **4 Chapter Four - Comparing asthma attack management within asthma guidelines worldwide and the GINA asthma strategy.**

### **4.1 Introduction**

The previous chapter detailed the results of my scoping review on a critical asthma attack. The scoping review revealed there was a lack of a consistent name and definition of this type of attack with a variety of clinical signs and objective measures. In order to supplement the findings of the scoping review, a review of asthma guideline, specifically on asthma attack management, was included to populate the eDelphi questionnaire. This chapter will present the methodology and findings of both a worldwide asthma guideline and Global Initiative for Asthma strategy review (GINA, 2019). The term near-fatal asthma will be used in this chapter as per the note on terminology in section 1.5 that explains this is the current name used within asthma guidelines.

### **4.2 Asthma guidelines**

The British Thoracic Society published the first UK guidelines on acute and chronic management of asthma for adults in 1990 (British Thoracic Society, 1990). This guideline was the first to be created worldwide. In 1993, GINA was launched in collaboration with the National Heart, Lung, and Blood Institute, the National Institutes of Health (USA) and the WHO (Kroegel and Wirtz, 2009) and they produced their first strategy report in 1995 (Global Initiative for Asthma, 1995). The aim of the first consensus report on asthma treatment, was to bridge the gap between the various treatment options and to incorporate and implement innovative treatment forms into daily clinical practice. GINA is updated annually and offers a foundation for other asthma guidelines which are developed within specific countries (Kroegel, 2009).

Guidelines are formulated using an evidenced based approach. BTS/SIGN follow the principles of Grading of Recommendations Assessment, Development and Evaluation (GRADE) a common, sensible and transparent approach to grading quality (or certainty) of evidence and strength of recommendations (Guyatt et al., 2008). However the methodology used by BTS/SIGN is described in SIGN 50: a guideline developer's handbook (SIGN, 2019). This approach is not replicated by GINA because of the major resource challenges it would present with annual updates. They have a preference to review the emerging evidence within a scientific committee and along with considering the different levels of evidence (e.g. Level A – randomised controlled trials or meta-analyses), they also consider how this can be implemented into practice within different clinical settings worldwide. Some of the methodological principles and recommendations from both BTS/SIGN and GINA have been incorporated in the development of the other guidelines included within this review which also include country specific approaches to management.

It is not known whether guidelines have improved the care of people with asthma however they have reduced variation in diagnosis and treatment of this complex disease (Fowler et al., 2018). Reddel, who is the current Chair of the GINA scientific committee and co-authors explain that, despite guidelines being available, they are not necessarily being implemented into practice and they need to be presented to clinicians in a more meaningful way (Reddel et al., 2015). Local adaptation of guidelines is evident from internet searches and this would suggest that some clinicians have been addressing this issue. The variability of advice contained within guidelines developed for acute asthma management worldwide is unknown and to my knowledge, there are no current studies available which have investigated this.



### 4.3 Aims

To identify asthma guidelines worldwide and compare definitions and management of acute asthma attacks across the spectrum of severity including NFA. The results of this review were used to populate the first round questions for an eDelphi (see section 5.8) with an aim to reach a consensus definition of NFA.

### 4.4 Methods

The websites for the International Primary Care Respiratory Group (IPCRG) [www.theipcr.org](http://www.theipcr.org) and the Global Asthma Network (which operates from Auckland, New Zealand) [www.globalasthmanetwork.org](http://www.globalasthmanetwork.org) act as a repository for international asthma guidelines and were used to identify guidelines published from 2009 until 2019 (Box 3). Although the GINA report is an integrated evidence based strategy rather than a guideline, for the purposes of this comparison study, I will refer to it as a guideline aligning terminology. I chose a ten year period as I felt that any guideline written out with this timeframe may be outdated and that Country may have transitioned to the GINA (worldwide) guideline (e.g. the 2007 USA guideline National Asthma Education and Prevention Program (NAEPP) has been superseded by the GINA guideline which updates annually (Morosco and Kiley, 2007)). At the time of the initial search in 2017, the Global Asthma Network repositories had not been updated since 2013. I anticipated there may be a number of guidelines missing, therefore a contemporaneous search of 195 countries using both the University of Edinburgh library and Google Scholar was conducted. I used the search terms 'asthma guideline' and the name of a country. An updated search and analysis was conducted following publication of the updated British Guideline for the management of Asthma and it was noted at that time the Global Asthma Network had subsequently updated their repository (date accessed 23.10.2019) (BTS/SIGN, 2019). No new guidelines were identified. It is worthwhile noting the IPCRG no longer host their

repository and the web link is no longer active and I am unaware of when this was removed.

**BOX 3: SEARCH STRATEGIES FOR ASTHMA ATTACK GUIDELINES FROM INITIAL REVIEW IN 2017 AND UPDATED SEARCH IN 2019.**

Initial Search 2017

- IPCRG guideline repository –  
<http://www.theipcrq.org/display/ResMapping/Mapping+of+national+guidelines+used+by+primary+care>
- Global Asthma Network guideline repository  
<http://www.globalasthmanetwork.org/management/adult.php>  
<http://www.globalasthmanetwork.org/management/child.php>
- [Edinburgh University library](https://ed.primo.exlibrisgroup.com/)  
<https://ed.primo.exlibrisgroup.com/>  
using search terms asthma guideline and the name of a country
- Google scholar  
using search terms 'asthma guideline' and the name of a country

Subsequent search 2019

- IPCRG guideline repository  
– <http://www.theipcrq.org/display/ResMapping/Mapping+of+national+guidelines+used+by+primary+care>
- Global Asthma Network guideline repository  
<http://globalasthmanetwork.org/management/country.php>

Definitions of asthma severity were compared using clinical features, objective measurements and activities of daily living. Guidelines are typically presented as flowcharts of care, with additional information sourced within the text of the document. The defining features of acute asthma attacks were extracted to an excel spreadsheet, including objective measurements and clinical features. Additional notes were made on other variables as relevant. Some guidelines were not written in English, therefore Google translate was used for those written in Spanish (Spain, Chile, Columbia and Uruguay) and the translation facility on the webpage for Finland's guideline. Guidelines from Canada and Turkey, which did not include acute wheeze management, were excluded from this comparison study.

## **4.5 Analysis**

An excel spreadsheet was populated with information from the asthma guidelines. In order to allow comparison, I needed to align all terms, therefore small amendments were made in terminology (e.g. speaking few words became phrases). This was replicated from the method used in the scoping review (see section 3.4.5). Descriptive statistics were used to analyse the data.

## **4.6 Results**

Twenty seven (n=27) guidelines were identified. There were 17(n=17/27, 63%) combined adult and child guidelines which contained a single flowchart and ten (n=10/27, 37%) child specific guidelines (Table 16). There are two global guidelines (n=2/27), five European (n=5/27), four South American (n=4/27), seven Asian (n=7/27), two African (n=2/27) and two Oceanian (n=2/27) (Table 17).

**TABLE 16: Asthma guideline according to year, country, population and source of guideline.**

| Year | Country                | Adult (A) guideline | Paediatric (P) guideline | Source of guideline<br>Global Asthma Network (G) IPCRG (I)<br>UoE library (L) Google Scholar (GS) |   |   |    |
|------|------------------------|---------------------|--------------------------|---------------------------------------------------------------------------------------------------|---|---|----|
|      |                        |                     |                          | G                                                                                                 | I | L | GS |
| 2019 | GINA (worldwide)       | ✓                   | ✓                        |                                                                                                   |   | ✓ |    |
|      | United Kingdom         | ✓                   | ✓                        |                                                                                                   |   | ✓ |    |
|      | Saudi Arabia           | ✓                   | ✓                        | ✓                                                                                                 |   |   |    |
| 2017 | Japan                  | ✓                   | ✓                        | ✓                                                                                                 |   |   |    |
|      | New Zealand            |                     | ✓                        |                                                                                                   | ✓ |   |    |
| 2016 | New Zealand            | ✓                   |                          |                                                                                                   | ✓ |   |    |
| 2015 | France                 | ✓                   |                          | ✓                                                                                                 |   |   |    |
|      | India                  | ✓                   |                          |                                                                                                   |   |   | ✓  |
|      | Ireland                | ✓                   |                          |                                                                                                   |   |   | ✓  |
| 2014 | Australia <sup>5</sup> | ✓                   |                          |                                                                                                   | ✓ |   |    |
|      | Malaysia               |                     | ✓                        | ✓                                                                                                 |   |   |    |
| 2013 | Argentina              | ✓                   |                          |                                                                                                   |   |   | ✓  |
|      | Chile                  | ✓                   |                          |                                                                                                   | ✓ |   |    |
|      | China                  | ✓                   |                          | ✓                                                                                                 |   |   |    |
|      | Columbia               | ✓                   |                          | ✓                                                                                                 |   |   |    |
|      | Ireland                |                     | ✓                        |                                                                                                   |   |   | ✓  |
|      | South Africa           |                     | ✓                        | ✓                                                                                                 |   |   |    |
|      | UAE                    |                     | ✓                        |                                                                                                   |   |   | ✓  |
| 2012 | Finland                | ✓                   |                          | ✓                                                                                                 |   |   |    |
| 2011 | Chile                  |                     | ✓                        |                                                                                                   | ✓ |   |    |
|      | Uruguay                |                     | ✓                        | ✓                                                                                                 |   |   |    |
|      | Kenya                  | ✓                   |                          | ✓                                                                                                 |   |   |    |
| 2009 | Philippines            | ✓                   |                          |                                                                                                   |   |   | ✓  |
|      | Spain                  | ✓                   |                          | ✓                                                                                                 |   |   |    |

**TABLE 17: NUMBER OF GUIDELINES ACCORDING TO CONTINENT**

| Continent              | Guideline (s)<br>Adult (A) Paediatric (P)              |
|------------------------|--------------------------------------------------------|
| Global (n=2/27)        | GINA (A, P)                                            |
| Africa (n=2/27)        | Kenya, South Africa                                    |
| Asia (n=7/27)          | China, India, Japan, Malaysia, Philippines, Saudi, UAE |
| Europe (n=5/27)        | Finland, France, Ireland, Spain, UK                    |
| South America (n=4/27) | Argentina, Chile, Columbia, Uruguay                    |
| Oceania (n=2/27)       | Australia, New Zealand                                 |

<sup>5</sup> The web link to the Australian Asthma Guideline for 2014 is no longer available.

## **4.7 The categorisation of asthma severity**

Asthma attacks are categorised into the following categories: mild, moderate, severe and life threatening. NFA was also recognised as another type of attack, in addition to life threatening asthma, however was not included in any flowchart for guidance on management.

Mild attacks were included in 11 (n=11/27, 40%) of the guidelines with an additional three (n=3/27, 11%) grouping mild and moderate management together. Mild attacks were not mentioned in 13 (n=13/27, 48%) of the guidelines. Moderate attacks were included in 23 guidelines (n=23/27, 85%). Severe asthma attacks were included in 25 guidelines (n=25/27, 92%). One additional guideline (n=1/27, 4%) from France, grouped severe and life threatening attacks together. Life threatening asthma was included in 26 (n=26 /27, 96%). NFA was discussed in 12 (n=12/27, 44%) guidelines, all of which included severe and life threatening attacks therefore NFA was recognised as a separate entity. There was acknowledgement of the level of severity of this attack and the increased risk of dying from an asthma attack. NFA is described as an event which increases PaCO<sub>2</sub> (n=3/13, 23%), will result in mechanical ventilation (n=5/13, 38%) and may cause death (n=1/13, 8%) therefore all of these variables were included in the eDelphi questionnaire.

### **4.7.1 Objective measurements**

The following objective measurements were identified in the guidelines: Pulse arterial oxygen saturation (SpO<sub>2</sub>), peak flow rate (PEFR), heart rate (HR), respiratory rate (RR), blood pressure (BP), pulsus paradoxus and blood gas parameters (PaCo<sub>2</sub> and PaO<sub>2</sub>).

#### 4.7.1.1 Pulse arterial oxygen saturation (SpO<sub>2</sub>)

It is recommended that oxygen saturations should be maintained between 94%-98% for an adult or child during an asthma attack, who may be prescribed supplemental oxygen therapy in order to achieve this value (O'Driscoll et al., 2017, BTS/SIGN, 2019). Table 18 provides the mode (the value that appears most frequently) and range of values of SpO<sub>2</sub> according to severity of attack within the guidelines.

**TABLE 18: SpO<sub>2</sub> ACCORDING TO LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing SpO <sub>2</sub> data | SpO <sub>2</sub> (in room air) mode | SpO <sub>2</sub> (in room air) range |
|------------------|------------------------------------------------------|-------------------------------------|--------------------------------------|
| Mild             | 11/27 (41%)                                          | >95%                                | >92% - ≥96%                          |
| Moderate         | 18/27 (67%)                                          | 90% -95%                            | <90% - 95%                           |
| Severe           | 21/27 (78%)                                          | ≤90%                                | ≤90% - 95%                           |
| Life threatening | 16/27 (59%)                                          | <90%                                | <90% - <92%                          |

#### 4.7.1.2 Peak expiratory flow rate (PEFR)

A peak expiratory flow rate (PEFR) is a measurement of how fast air can be expelled from the lungs during forceful expiration and is measured in Litres per minute (L/min) (Callahan et al., 2010). It can be a useful tool for home monitoring and values are often incorporated within a personalised asthma action plan to guide care especially during an asthma attack. Predicted values for children are based on height or best ever value (which may be above or below predicted value) but for adults include age and sex. A percentage of the predicted value is presented in clinical practice to assist in the recognition of attack severity however is best used in conjunction with other variables e.g. SpO<sub>2</sub> and RR. Table 19 provides the mode and range of values for PEFR according to severity of attack within guidelines.

**TABLE 19: PEFR (% predicted) according to level of asthma attack severity.**

| Attack severity  | Number of guidelines providing PEFR data | PEFR mode | PEFR range                        |
|------------------|------------------------------------------|-----------|-----------------------------------|
| Mild             | 11/27 (41%)                              | ≥80%      | >70% - 90%                        |
| Moderate         | 18/27 (67%)                              | ≥50%      | 40% - 95%                         |
| Severe           | 20/27 (74%)                              | ≤50%      | 30% - 60%                         |
| Life threatening | 16/27 (59%)                              | <30%      | unable to perform –<br><25% - 50% |

#### 4.7.1.3 Heart rate, respiratory rate and blood pressure

Heart rate (HR), respiratory rate and blood pressure demonstrate normal ranges across all ages during health, with age dependant increases in children. Tables 20, 21 and 22 provides the mode and range of values for HR (beats per minute), RR (breaths per minute) and blood pressure (BP) that are considered by guidelines to be consistent with severity of an asthma attack at each level.

**TABLE 20: HR (BEATS PER MINUTE) BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing HR data | HR mode (beats per minute) | HR (beats per minute) range |
|------------------|----------------------------------------|----------------------------|-----------------------------|
| Mild             | 7/27 (26%)                             | <100                       | Normal - <100               |
| Moderate         | 13/27 (48%)                            | 100-120                    | 100 - 125                   |
| Severe           | 16/27 (59%)                            | ≥120                       | 100 - >130                  |
| Life threatening | 15/27 (55%)                            | bradycardia                | bradycardia -<br>>120       |

**TABLE 21: RR (BREATHS PER MINUTE) BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing RR data | RR mode (breaths per minute) | RR range (breaths per minute) |
|------------------|----------------------------------------|------------------------------|-------------------------------|
| Mild             | 12/27 (44%)                            | increased                    | 19 - increased                |
| Moderate         | 15/27 (55%)                            | increased                    | normal - >40                  |
| Severe           | 22/27 (81%)                            | >30                          | increased - >40               |
| Life threatening | 7/27 (26%)                             | poor effort                  | poor effort - >30             |

**TABLE 22: BP BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing BP data | BP mode     | BP range          |
|------------------|----------------------------------------|-------------|-------------------|
| Mild             | 0                                      | No data     | No data           |
| Moderate         | 1/27 (4%)                              | normal      | normal            |
| Severe           | 1/27 (4%)                              | normal      | normal            |
| Life threatening | 7/27 (26%)                             | hypotensive | hypotensive (low) |

#### 4.7.1.4 Pulsus paradoxus

Pulsus paradoxus is defined as a fall of systolic blood pressure of >10 mmHg during the inspiratory phase of respiration (Hamzaoui et al., 2013). In practice this was typically measured using a manual sphygmomanometer however it was a time consuming procedure (2-5 minutes) made more challenging by tachypnoea and a noisy clinical environment during emergency treatment for an asthma attack, as such it is less commonly used as a clinical sign. In an intensive care context however invasive monitoring of blood pressure using an arterial catheter provides an accurate real-time assessment of pulsus paradoxus. Table 23 provides the mode and range of values for pulsus paradoxus according to severity of attack at each level.

**TABLE 23: PULSUS PARADOXUS (MMHG) BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing pulsus paradoxus data | pulsus paradoxus (mmHg) mode | pulsus paradoxus (mmHg)range       |
|------------------|------------------------------------------------------|------------------------------|------------------------------------|
| Mild             | 5/27 (18%)                                           | absent or < 10mmHg           | absent or < 10mmHg                 |
| Moderate         | 4/27 (15%)                                           | 10 - 20mmHg                  | 10 - 25mmHg                        |
| Severe           | 5/27 (18%)                                           | >25mmHg                      | 20 - 40mmHg                        |
| Life threatening | 5/27 (18%)                                           | absent, suggests fatigue     | absent, suggests fatigue - >40mmHg |

#### 4.7.1.5 Blood gases

Blood gas measurements should be considered if there are features of life threatening asthma not responding to treatment (BTS/SIGN, 2019). Samples are taken via three different methods: capillary blood gas (CBG), venous blood gas (VBG) or arterial blood gas (ABG). ABG is considered to be the gold standard however CBG or VBG



sampling are used as an alternative and non-invasive method to arterial blood gas sampling, which requires the insertion of an arterial line or arterial puncture (Yıldızdaş et al., 2004). All are used for the analysis of a patient's adequacy of ventilation and estimating acid-base balance with arterial sampling providing additional information (Vasileiadis et al., 2019). Tables 24 and 25 provide the mode and range of values for PaCO<sub>2</sub> and PaO<sub>2</sub> according to severity at all levels.

**TABLE 24: PaCO<sub>2</sub> (MMHG/ kPa) BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing PaCO <sub>2</sub> data | PaCO <sub>2</sub> mode mmHg (kPa) | PaCO <sub>2</sub> range mmHg/ (kPa) |
|------------------|-------------------------------------------------------|-----------------------------------|-------------------------------------|
| Mild             | 7/27 (26%)                                            | <42 (5.6)                         | <35 – 45<br>(<4.6 - <5.6)           |
| Moderate         | 7/27 (26%)                                            | < 45 (6)                          | <40 – 45<br>(<5.33 - <5.6)          |
| Severe           | 7/27 (26%)                                            | ≥ 42 (5.6)                        | < 40 - 60<br>(<5.3 - 8)             |
| Life threatening | 12/27 (44%)                                           | >45 (6)                           | 35 – >60<br>(4.6 - >8)              |

**TABLE 25: PaO<sub>2</sub> (MMHG/ kPa) BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing PaO <sub>2</sub> data | PaO <sub>2</sub> mode mmHg (kPa) | PaO <sub>2</sub> range mmHg (kPa) |
|------------------|------------------------------------------------------|----------------------------------|-----------------------------------|
| Mild             | 4/27 (15%)                                           | normal                           | normal                            |
| Moderate         | 2/27 (7%)                                            | ≥ 60 (8)                         | ≥ 60 (8)                          |
| Severe           | 5/27 (18%)                                           | ≤ 60 (8)                         | 80 – 60 (10.6 – 8)                |
| Life threatening | 8/27 (30%)                                           | ≤60 (8)                          | ≤ 60 (8)                          |

#### 4.7.2 Clinical features

During an asthma attack greater pressure is needed to push air through the bronchus, resulting in the increased use of accessory muscles (see section 2.6). During an attack there are also changes in chest sounds, posture and behaviour. Tables 26 – 29 represent the mode and range of values for accessory muscle use, chest sounds, posture and behaviour.

#### 4.7.2.1 Accessory muscle use

**TABLE 26: ACCESSORY MUSCLE USE BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing accessory muscle use data | Accessory muscle use mode             | Accessory muscle use range                                      |
|------------------|----------------------------------------------------------|---------------------------------------|-----------------------------------------------------------------|
| Mild             | 9/27 (33%)                                               | no                                    | no - mild                                                       |
| Moderate         | 12/27 (44%)                                              | mild                                  | no - moderate                                                   |
| Severe           | 16/27 (59%)                                              | accessory muscle use                  | accessory muscle use                                            |
| Life threatening | 17/27 (63%)                                              | paradoxical thoracoabdominal movement | poor respiratory effort - paradoxical thoracoabdominal movement |

#### 4.7.2.2 Chest sounds

**TABLE 27: CHEST SOUNDS BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing chest sounds data | Chest sounds mode | Chest sounds range             |
|------------------|--------------------------------------------------|-------------------|--------------------------------|
| Mild             | 11/27 (41%)                                      | mild wheeze       | mild – moderate wheeze         |
| Moderate         | 11/27 (41%)                                      | moderate wheeze   | moderate wheeze                |
| Severe           | 12/27 (44%)                                      | moderate wheeze   | moderate wheeze – silent chest |
| Life threatening | 22/27 (81%)                                      | silent chest      | silent chest                   |

#### 4.7.2.3 Positioning

**TABLE 28: POSTURE BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing positioning data | Positioning mode      | Positioning range     |
|------------------|-------------------------------------------------|-----------------------|-----------------------|
| Mild             | 6/27 (22%)                                      | can lie down          | can lie down          |
| Moderate         | 6/27 (22%)                                      | prefers sitting       | prefers sitting       |
| Severe           | 7/27 (26%)                                      | hunched forward       | hunched forward       |
| Life threatening | 3/27 (11%)                                      | breathless lying flat | breathless lying flat |

#### 4.7.2.4 Behaviour

**TABLE 29: BEHAVIOUR BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing behaviour data | Behaviour mode     | Behaviour range                                                             |
|------------------|-----------------------------------------------|--------------------|-----------------------------------------------------------------------------|
| Mild             | 7/27 (26%)                                    | may be agitated    | normal - may be agitated                                                    |
| Moderate         | 11/27 (41%)                                   | agitated           | normal - agitated                                                           |
| Severe           | 12/27 (44%)                                   | agitated           | agitated                                                                    |
| Life threatening | 23/27 (85%)                                   | drowsy or confused | confusion, impaired consciousness, drowsy, altered mental status, exhausted |

#### 4.7.3 Activities of daily living

Educating patients and their families on how an asthma attack can affect their activities of daily living, in association of the clinical signs of cough, wheeze and chest tightness, could provide benefit in helping them recognise when to get medical assistance. Tables 30 – 33 provide the mode and range of a patient's ability to talk (Table 30), drink/feed (Table 31), walk (Table 32) and sleep (Table 33) according to the level of asthma attack severity.

**TABLE 30: THE ABILITY TO TALK BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing data on the ability to talk | Ability to talk mode | Ability to talk range         |
|------------------|------------------------------------------------------------|----------------------|-------------------------------|
| Mild             | 10/27 (37%)                                                | in sentences         | in sentences                  |
| Moderate         | 21/27 (78%)                                                | phrases              | normal, sentences, phrases    |
| Severe           | 24/27 (89%)                                                | words                | unable to talk – single words |
| Life threatening | 9/27 (33%)                                                 | unable to talk       | unable to talk – single words |

**TABLE 31: THE ABILITY TO FEED BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing data on the ability to drink/ feed | Ability to drink/ feed mode | Ability to drink/ feed range |
|------------------|-------------------------------------------------------------------|-----------------------------|------------------------------|
| Mild             | 1/27 (4%)                                                         | normal                      | normal                       |
| Moderate         | 5/27 (18%)                                                        | difficult                   | difficult                    |
| Severe           | 5/27 (18%)                                                        | difficult                   | too breathless - difficult   |
| Life threatening | 1/27 (4%)                                                         | unable                      | unable                       |

**TABLE 32: THE ABILITY TO WALK BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing data on the ability to walk | Ability to walk mode | Ability to walk range            |
|------------------|------------------------------------------------------------|----------------------|----------------------------------|
| Mild             | 8/27 (30%)                                                 | breathless           | slightly breathless - breathless |
| Moderate         | 3/27 (11%)                                                 | difficult            | can walk - difficult             |
| Severe           | 2/27 (7%)                                                  | difficult            | difficult                        |
| Life threatening | 2/27 (7%)                                                  | cannot walk          | cannot walk                      |

**TABLE 33: THE ABILITY TO SLEEP BY LEVEL OF ASTHMA ATTACK SEVERITY.**

| Attack severity  | Number of guidelines providing data on the ability to sleep | Ability to sleep mode | Ability to sleep range |
|------------------|-------------------------------------------------------------|-----------------------|------------------------|
| Mild             | 1/27 (4%)                                                   | can sleep             | can sleep              |
| Moderate         | 1/27 (4%)                                                   | occasionally wake up  | occasionally wake up   |
| Severe           | 1/27 (4%)                                                   | disturbed             | disturbed              |
| Life threatening | 1/27 (4%)                                                   | disturbed             | disturbed              |

#### 4.7.4 Near fatal Asthma (NFA)

NFA is described in 12/27 (44%) of the guidelines however it is not included in the flowcharts for management. NFA is not defined however there are a number of features that are listed in the guidelines as being associated with the event: mechanical ventilation 5/27 (18%), raised PaCO<sub>2</sub>, 3/27 (11%), respiratory arrest 2/27 (7%), fatal asthma 1/27 (4%) and intensive care treatment if apnoeic or in a coma 1/27 (4%).

## 4.8 Discussion

This review of asthma guidelines has identified 27 guidelines from 20 countries. Guidelines referred to both adults and children. They provided clinical features and objective measurements by level of asthma severity. This limited information for NFA supports my strategy of examining related severity classes for factors potentially associated with NFA that could inform a first round eDelphi.

Within the guidelines, objective measurements of SpO<sub>2</sub>, PEFR, RR and HR were more likely to be included, the greater the severity of the attack (mild ~40% v severe ~75%). Variance of objective measurements with increasing severity are described in relation to normal physiological parameters. Early detection of changes within these objective measurements would be important to help identify those potentially at risk. Early identification of those at risk could prompt the use of appropriate emergency medications and appropriate clinical review. Guidelines place little emphasis on BP and pulsus paradoxus which may suggest they are regarded as either poor indicators of clinical severity or are difficult to implement in practice. The analysis of blood gases (PaO<sub>2</sub> and PaCO<sub>2</sub>) are usually only performed with signs of deteriorating asthma, usually when the attack is severe, life threatening or near fatal, which was reflected in the comparisons (see Tables 24 and 25) when a rising PaCO<sub>2</sub> and falling PaO<sub>2</sub> were included in flowcharts and text. There was no direction given on how the blood gas sample should be obtained however in clinical practice a CBG or VBG would be more common in paediatrics (Yıldızdaş et al., 2004, Vasileiadis et al., 2019) and by arterial sampling (ABG) in adults (Eid, 2020) .

A patient experiencing an asthma attack is observed on presentation to an emergency department or primary care and judgements on clinical severity are made taking into account features on clinical examination. In the reviewed guidelines, clinical features which feature most commonly (~40%) are the presence of wheeze, work of breathing

and the patient's behaviour. The patient can often experience wheeze, which can initially only be heard by a stethoscope, progressing to it being heard audibly. Wheeze however can be absent in a life threatening episode, when the chest is considered to be silent. This is an important inclusion in guidelines as the absence of wheeze may falsely reassure a less experienced clinician, rather than alert them to the patient's inability to generate enough airflow to wheeze, due to severe airway obstruction or fatigue. Respiratory effort, or work of breathing, can initially be difficult to assess in a fully clothed patient, however the use of the sternocleidomastoid muscle (situated around the neck area) is usually visible on inspection and effort can be noted. This was regarded as important in assessing severe attacks, however in a life threatening attack the breathing pattern changes to a paradoxical thoracoabdominal movement. This means that during inspiration, the chest contracts, and during expiration, it expands, the opposite of normal respiration. This is accompanied by unusual movements in the abdomen, which may also move in when a person inhales and out when they exhale. Work of breathing and respiratory effort featured in the severe to life threatening guidelines (~60%), alongside increasing agitation (behaviour change) and cyanosis (bluish discolouration to the skin due to inadequate oxygenation) are important signs of deteriorating asthma, which can be discussed with patients and families as part of supported self-management, alongside the activities such as the ability to talk, eat and drink. Only a small proportion (~5 - 20%) of the guidelines included features of ability to feed, walk and sleep, however these are factors which would have an impact on a patient, in association with clinical features, which would prompt them to get urgent medical review. The ability to talk is included in the majority of the guidelines with the inability to speak regarded as a feature of life threatening asthma.

## **4.9 Strengths and limitations**

The strengths of this chapter are that it is a comprehensive comparison of acute asthma guidelines which are available as a web resource and have been implemented into clinical practice over the past ten years. The comparison highlights the commonalities and differences between the guidelines and factors which guideline committees believe to be important for clinicians making decisions about attack severity, which prompts medical management. This review has provided parameters for objective measurements which were not included within the scoping review and can be added to the eDelphi questionnaire. Although NFA is acknowledged as a separate entity in excess of a life threatening attack, none of the guidelines provide a definition of the event, reinforcing the need to provide a definition for future use. Guidelines not available in English were translated rather than being excluded from the study.

Although the Global asthma network repository was recently updated to include the 2019 guidelines, there is a possibility that some current guidelines have been overlooked and not included in this comparison. However, I utilised an additional search strategy and to my knowledge, I have included all guidelines which were published and available online as of 23.10.2019.

## **4.10 Conclusion**

Guidelines addressing acute asthma management, lack consistency in the features provided to aid recognition of severity, in particular for objective versus clinical signs. The range of values for objective measurements is wider for milder attacks and this narrows as attack severity increases, in particular, a life threatening attack. The range is narrower with clinical signs. The mode identified within the clinical signs tended to be the same as the range and had a minor variation which is presented in the tables. There was agreement across the guidelines on the ability to talk, feed, walk and sleep.

Although NFA is mentioned in 12 of the guidelines, none provide a case definition. The features provided within guidelines to support a diagnosis of NFA and subsequent management are highly variable. A clear definition with recognised features may help clinicians provide better support by the early use of intensive pharmacological treatment or ventilatory support, either invasive or non-invasive. A more precise definition for NFA could also help improve surveillance and support the ability to measure the effect of interventions within clinical trials. This comparison study has enhanced the number of variables identified, predominantly with objective measurements, in the scoping review (see chapter 3). These were included within the eDelphi questionnaire (chapter 5).

#### **4.11 Summary and next steps**

In this chapter I have reported on the results of a review comparing assessment and management of acute asthma attacks within asthma guidelines worldwide and the GINA asthma strategy. The findings from this chapter will help inform the round one eDelphi questionnaire in chapter five.

In the next chapter I will present the aims, methods and results of an eDelphi study which aimed to gain a consensus definition of NFA and address the aims of component one of my PhD study.



## **5 Chapter 5: Defining Near Fatal Asthma: an international eDelphi study.**

### **5.1 Introduction**

National and international asthma guidelines, such as British Thoracic Society (BTS)/ Scottish Intercollegiate Guidelines Network and Global Initiative for Asthma, categorise the severity of asthma attacks into mild, moderate and severe/life threatening episodes, with guidance on clinical signs and objective measurements identified for each (BTS/SIGN, 2019, GINA, 2020). Patients in general will be unaware of the category of their asthma attacks and many who experience a severe asthma attack are not considered by clinicians at immediate risk of death.

In this chapter, as we evolve a name for this penultimate event, I will refer to this event as a 'critical asthma attack', until the preferred name is determined. The scoping review of a critical asthma attack in chapter three and review of global asthma guidelines in chapter four helped to inform the research team of the current terminology used in research and practice. Status asthmaticus is the term used to describe this event within Medical Subject Headings (MeSH) (Box 4) and the International Classification of Diseases (ICD-11) (World Health Organization, 2018) (Box 5).

**Box 4: ASTHMA MeSH DESCRIPTOR DATA**

Adapted from Asthma MeSH descriptor data 2021  
(<https://meshb.nlm.nih.gov/record/ui?ui=D001249>)

**MeSH tree structures****Asthma [C08.127.108]**

- Asthma, Aspirin-induced [C08.127.108.054]
- Asthma, Exercise-Induced [C08.127.108.110]
- Asthma, Occupational [C08.127.108.495]
- Asthma-Chronic Obstructive Pulmonary Disease Overlap Syndrome [C08.127.108.688]
- Status Asthmaticus [C08.127.108.880]

**Box 5: ICD-11 SCORING TOOL FOR ASTHMA ATTACKS**

Adapted from ICD-11 International Classification of Diseases (World Health Organization, 2018)

|         |                                                           |
|---------|-----------------------------------------------------------|
| CA23    | <b>Asthma</b>                                             |
| CA23.3  | Unspecified <b>asthma</b>                                 |
| CA23.32 | Unspecified <b>asthma</b> , uncomplicated                 |
| CA23.0  | Allergic <b>asthma</b>                                    |
| CA23.1  | Non-allergic <b>asthma</b>                                |
| CA23.12 | Non-allergic <b>asthma</b> , uncomplicated                |
| CA23.10 | Non-allergic <b>asthma</b> with exacerbation              |
| CA23.11 | Non-allergic <b>asthma</b> with status <b>asthmaticus</b> |
| CA23.30 | Unspecified <b>asthma</b> with exacerbation               |
| CA23.31 | Unspecified <b>asthma</b> with status <b>asthmaticus</b>  |
| CA23.00 | Allergic <b>asthma</b> with exacerbation                  |
| CA23.02 | Allergic <b>asthma</b> , uncomplicated                    |
| CA23.01 | Allergic <b>asthma</b> with status <b>asthmaticus</b>     |
| CA23.2  | Other specified forms of <b>asthma</b> or bronchospasm    |
| CA23.20 | Aspirin-induced <b>asthma</b>                             |
| CA23.22 | Cough variant <b>asthma</b>                               |

Status asthmaticus has been defined using definitions as disparate as firstly, failure to respond to beta-agonists and theophylline or secondly, a small group of severe

asthmatics who present with severe bronchospasm and CO<sub>2</sub> retention, who become exhausted, fail to respond to intensive treatment, and require mechanical ventilation (Otte and Fireman, 1991, Cox et al., 1991). This lack of a specific definition has led to other terms being introduced including near fatal asthma, severe life threatening asthma with progressive respiratory failure and critical asthma syndrome (see section 3.4.2). The lack of consistency with definition, will lead to difficulty in identifying the incidence of a critical asthma attack and designing research studies regarding clinical care. There is evidence that those individuals who have experienced such an event are at significant risk of experiencing a similar attack in the future or death (Boulet et al., 1991, Triasih et al., 2011).

This chapter provides a description of the approach I used to integrate the potential characteristics of a critical asthma attack, identified in the scoping review and global asthma guidelines review, in order to create an agreed name for this event and a definition which achieved consensus by a panel of international experts.

## **5.2 Aims**

- To gain an international clinical consensus name and definition for a 'critical asthma attack' to enable the frequency of defined attacks to be measured, against which future interventions can be trialled, to reduce these and asthma deaths.
- To utilise the consensus name and definition to identify participants for the NFA qualitative study

## **5.3 Methods**

As part of a research team with Steve Cunningham (SC) and Louise Fleming (LF), I undertook a modified electronic Delphi (eDelphi). An eDelphi is based on the traditional Delphi process developed by the US Research and development Corporation, RAND in 1948. This technique was developed at the beginning of the

cold war to forecast the impact of technology on warfare (Custer et al., 1999). The main premise of the Delphi method is based on the assumption that group opinion is more valid than individual opinion and it has been defined as a multi-staged survey which attempts ultimately to achieve consensus on an important issue (McKenna, 1994). Furthermore, it is an iterative process which is designed to combine expert opinion into group consensus (Lynn et al., 1998).

In addition to the eDelphi method, the other two most commonly used approaches to achieve consensus are the nominal group technique and the consensus development conference (Arakawa & Bader, 2022).

The nominal group technique is a structured face-to-face interaction usually involving 5 to 12 participants. It was designed by Delbecq and Van de Ven and comprises four key stages: silent generation, round robin, clarification and voting (Delbecq et al., 1975). There is an option to add further group discussion and anonymous voting if necessary to reach consensus. The main advantages of the nominal group technique are the potential to discuss and debate topics lacking consensus face to face with a group of experts. This provides the opportunity for more robust idea generation. The disadvantages are the smaller number of participants and that more vocal participants may unduly influence the group (Humphrey-Murto et al., 2017, McMillian et al., 2016).

The consensus development conference approach is a face-to-face interactive method usually involving 10 panel members. This method was developed by the National Institutes of Health in US in 1977 (Murphy et al., 1998). Its process involves using iterative face-to-face meetings of experts. A small group of experts, who are not involved in the decision-making process, present evidence on the particular issue. Panel members then ask questions for clarity before deliberating on the topic with direction from a chair person to try and achieve consensus. The main advantage of this method is the debate and discussion between panel members. The main

disadvantages are time and the added costs of having key experts presenting information (Arakawa & Bader, 2022).

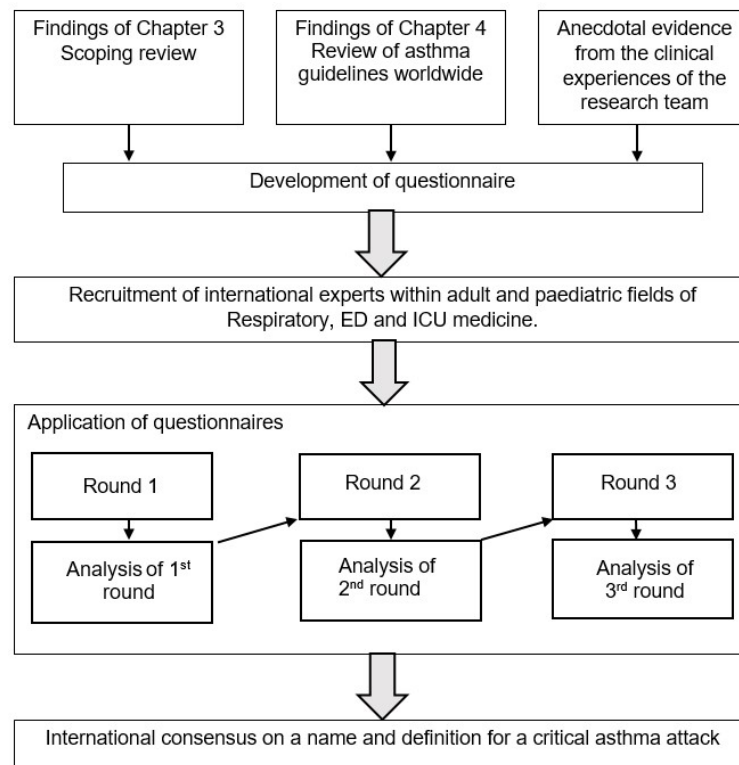
As a team we decided not to use these approaches as it would have been challenging to co-ordinate meetings with key experts in this field. We did not have additional funding to cover expenses, such as travel, and would have been limited to engagement with participants from the UK. We were keen to engage with a wide variety of clinicians globally. There were also time constraints as achieving the consensus name and definition of this attack was crucial for recruitment to the qualitative research studies with parents and young adults. Conducting a global eDelphi via email allowed us to reach a diverse population of participants who perceived themselves to be experts in this field in a timeframe which was appropriate for this PhD study.

There were 3 rounds to the study (Table 34) and the method is further explained in Figure 9 below.

**TABLE 34: DESCRIPTION OF ACTIVITY FROM EACH OF THE 3 ROUNDS OF THE eDELPHI STUDY**

| <b>Round</b> | <b>Description of activity</b>                                                                                                       |
|--------------|--------------------------------------------------------------------------------------------------------------------------------------|
| <b>1</b>     | Naming the event, identification of key features from clinical signs, objective measurements and other signs with room for free text |
| <b>2</b>     | Naming the event, rescoring using feedback from summary of all participants                                                          |
| <b>3</b>     | Agreeing the name of the event, choosing a definition, agreeing on objective measurements                                            |

**FIGURE 9: THE METHOD USED TO UNDERTAKE AN INTERNATIONAL eDELPHI STUDY**



The electronic survey was developed using Online Surveys, ([www.onlinesurveys.ac.uk](http://www.onlinesurveys.ac.uk)) formerly Bristol Online Surveys, as this was the preferred software used by the University of Edinburgh and had a more professional appeal than Survey Monkey®. An online survey enabled the broadest geographical reach for the survey to enhance its global generalisability. The survey was distributed via an email address) created for the study between February 2018 and June 2018. The initial email included an invitation and hyperlink to take part in the study and a Participant Information Sheet (PIS). The PIS provided information about the study, informed participants of the consent procedure and freedom to withdraw at any stage. Consent was signed as a yes/ no option on the front page of the survey, prior to entering into each round of the study. Participants were encouraged to complete all three rounds advising that the time taken to complete each round would decrease and

that their responses were valuable to the outcome of the study. Three emails were sent each round, one with the survey link which included a closing date and reminders at one week (reminder 1) and two days (reminder 2) before the study closed. The initial round was open for four weeks followed by the two subsequent rounds, open for two weeks each. There was an option to increase the closure date to encourage participants to complete the third round. Withdrawals were classed as those who failed to complete subsequent rounds despite sending the invitation and reminders to complete the survey and their names were withdrawn from the email mailing list for future rounds.

#### **5.4 Ethics**

Ethical Approval for the eDelphi study was obtained from the Usher Research Ethics Group, The Usher Institute of Population Health Sciences and Informatics, University of Edinburgh (Ethics application number 1746).

There was a delay in achieving ethical approval from the university which was granted three months after initial submission. The Usher Institute rely on staff members to volunteer to review submissions. My initial application was reviewed in November 2017 and suggestions for changes were made. I subsequently resubmitted my application with changes in December 2017. The resubmission was reviewed by a different member of staff who made a significant amount of additional recommendations, including the preparation of a participant information sheet, which were made and resubmitted within a few days. Approval was subsequently granted in January 2018. (Appendix 1)

#### **5.5 Recruitment of experts**

Medical consultants (or equivalent in other countries e.g. Board Certified) were recruited via two methods, targeted email or via a global email sent by groups,

colleges and societies (table 35). The email included an attachment of the participant information sheet (Appendix 2 & 3)

**TABLE 35: RECRUITMENT SOURCES WITH NUMBERS OF POTENTIAL PARTICIPANTS THE RECRUITMENT EMAILS REACHED.**

| Speciality<br>Recruitment source                             | Respiratory       | Emergency<br>Medicine | Critical Care<br>medicine |
|--------------------------------------------------------------|-------------------|-----------------------|---------------------------|
| Targeted email                                               | 84 (adult & paed) | 33                    | 36                        |
| British Paediatric Respiratory Society (BPRS)                | 384 (paed only)   |                       |                           |
| European Academy for Allergy and Clinical Immunology (EAACI) | 4328 (paed only)  |                       |                           |
| Ped-lung                                                     | 1369 (paed only)  |                       |                           |
| Australia and New Zealand Intensive Care Society (ANZICS)    |                   |                       | 900                       |
| Totals                                                       | 6165              | 33                    | 936                       |

\*shaded area represents participants have not been recruited from this medical discipline via the recruitment source\*

Numerous groups, colleges and societies were unable to circulate the eDelphi to their members for reasons which included; not being part of the research team, cost, ownership of data and local policy (Table 36)

**TABLE 36: DETAILS OF OTHER SOURCES OF RECRUITMENT CONTACTED AND RATIONALE FOR BEING UNABLE TO CIRCULATE THE SURVEY**

| College, Group or Society                           | Rationale for not circulating to members                                                                                                                                                         |
|-----------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Australasian College of Emergency Medicine (ACEM)   | The application to have the survey circulated to members would not have been reviewed for 8 weeks after submission which would have caused a delay in commencing round 1 of the survey.          |
| American College of Emergency Physicians (ACEP)     | They did not circulate surveys to members however had a Facebook page which I could post on. This post did not appear in the timeline and may not have been approved by the page administrators. |
| American Thoracic Society (ATS)                     | No response to 2 emails                                                                                                                                                                          |
| British Thoracic Society (BTS)                      | The BTS only circulated surveys which they had created and expected ownership of the data.                                                                                                       |
| Canadian Association of Emergency Physicians (CAEP) | They do not circulate surveys from those who are not members of CAEP                                                                                                                             |
| Canadian Critical Care Society (CCCS)               | \$500 to circulate the survey                                                                                                                                                                    |



| College, Group or Society                                    | Rationale for not circulating to members                                                                                                                                                                                                          |
|--------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Canadian Thoracic Society (CTS)                              | No response to 2 emails                                                                                                                                                                                                                           |
| European Respiratory Society (ERS)                           | They did not circulate surveys to members                                                                                                                                                                                                         |
| European Society for Emergency Medicine (EUSEM)              | No response to 2 emails                                                                                                                                                                                                                           |
| Intensive Care Society (ICS)                                 | No response to 2 emails                                                                                                                                                                                                                           |
| Paediatric Emergency Research Networks (PERN)                | PERN is a conglomerate of multiple smaller regional / national networks that provide the backbone for paediatric emergency research, and study proposals are usually vouched for within one of the networks prior to coming to PERN (i.e. PERUKI) |
| Paediatric Emergency Research in the UK and Ireland (PERUKI) | As per their terms of reference, they were unable to participate as we did not have a member of PERUKI on our study team                                                                                                                          |
| Paediatric Intensive Care Society (PICS)                     | They do not circulate surveys from those who are not members of PICS                                                                                                                                                                              |
| Royal College of Emergency Medicine (RCEM)                   | They do not circulate surveys from those who are not members of RCEM                                                                                                                                                                              |
| Society of Critical Care Medicine (SCCM)                     | \$4000 to circulate a survey                                                                                                                                                                                                                      |

As a research team we had considered including nurses and patients as experts, however specialist nurse's level of autonomy, practice and responsibilities differ within the United Kingdom and the patient view point, although important, may miss the important subtle warning signs identified by clinicians (Begley et al., 2013).

## 5.6 Population

Participants were asked to consider children from age 5 years to young adults aged 24 years. The rationale for selecting this age range is discussed in the qualitative methods chapter (see section 6.7).

## 5.7 Consent

Consent to participate in the eDelphi was obtained prior to each round. Participants ticked a box on the questionnaire. All participants received a personalised report of their responses from each of the eDelphi rounds, which provided confirmation of their consent.

## **5.8 eDelphi rounds one and two**

The aim of round one was to achieve consensus in naming the event and to gain consensus with the key features associated with the event, which was referred to as the “critical asthma attack”. Rather than having a completely free text round, which may have been perceived as a barrier to participation, the questionnaire was pre-populated as per the findings of the scoping review and worldwide asthma guideline summary in chapters three and four. There was some additional space available for free text responses. The following headings were used for each section:

- about the critical asthma attack
- clinical signs
- objective measurements
- other features
- future self-management

There was also a section to capture characteristics of the participants. Prior to distribution, the survey was piloted by staff in two different hospitals (Royal Hospital for Sick Children, Edinburgh and The Royal Brompton, London) and amended for clarity and to ensure there were no spelling mistakes. An option to tick an advanced setting of online surveys (to ensure compulsory responses) was missed in round one and led to some missing data. This was rectified for further rounds and participants had the opportunity to respond to the questions they had missed in round one in round two. In providing their responses, participants were asked to consider what differentiates a critical asthma attack from a severe asthma attack. Participants were asked to rank each item using a Likert scale of importance: 1 – Irrelevant, 2- Unimportant, 3 – Of equivocal importance, 4 – Important and 5 – Very important.

Participants were provided with free text boxes at the end of each section in round one, and asked to include additional names for the attack, additional features or clinical signs and to add values to objective measurements.

Anonymity within an eDelphi is not possible as respondents had to supply an email address to obtain their personalised feedback along with subsequent email links (Keeney et al., 2017). I was the only member of the research team who knew the identity and responses of the participants. They were all assigned a research number and a database was kept on a secure password protected university network.

The questionnaire data were analysed by Online Surveys functionality, which produced a comprehensive report. There was also a facility to export data to an excel spread sheet, for further analysis of free text data. Consensus was agreed, prior to the study commencing, at  $\geq 70\%$ , which was the same as the level set in another Delphi study, which hoped to gain consensus definition on a clinical condition (Simon et al., 2014). A combined response of either 4-5 (important) or 1-2 (irrelevant) was used with median and range of all ratings also calculated. Free text responses were analysed thematically (clinical features) or numerically (objective measurements).

Each participant was provided with an individualised report of their responses, generated by online surveys. This was accompanied by a condensed summary of responses which was colour coded, green  $\geq 70\%$  consensus, amber 50-69% consensus and red  $\leq 49\%$  consensus. In round two, participants were asked to reconsider their scores in relation to the feedback and rescore accordingly. Free text boxes were removed and additional questions were included in response to the feedback from the free text in round one. The same instructions applied as per round one. Similarly to round one, all participants received the individualised report and summary of responses after round two was completed.

## **5.9 eDelphi round three**

For the third and final round, participants were provided with a choice between the two most popular chosen names for the attack: near-fatal asthma and severe life-threatening asthma. They were also provided with a definition stem with four options to consider and variables for four objective measurements.

## **5.10 Results**

The survey link was emailed to approximately 7134 potential participants with cross over expected between targeted emails and distribution lists. The groups were consultants within the fields of Respiratory (R), Emergency Department (ED) and Critical Care (CC) medicine. I was aware that some of the recipients of the emails may not have had expertise in acute asthma management of our desired populations, therefore did not participate in the study. As a research team, our aim was to have as many participants as possible, with representation across the globe.

A total of 159 participants took part in round one, 116 (73%) completed two rounds and 104 (65%) completed all three rounds. Attrition rates between round one and round two, may be attributed to my unexpected period of illness after round one resulting in a delay in circulation of round two, time of year (early summer), or personal choice not to continue. A summary of characteristics of the participants according to clinical practice is presented in Table 37 with a complete table of participant characteristics, who completed all three rounds of the study, presented in Table 38.

**TABLE 37: CHARACTERISTICS OF PARTICIPANTS ACCORDING TO CLINICAL PRACTICE WHO COMPLETED ALL THREE ROUNDS OF THE EDELPHI STUDY.**

| Discipline             | numbers | Discipline        | numbers |
|------------------------|---------|-------------------|---------|
| Paediatric Respiratory | 54      | Adult Respiratory | 20      |
| Paediatric CC          | 07      | Adult CC          | 12      |
| Paediatric ED          | 11      | Adult ED          | 00      |
| Paediatric Total       | 72      | Adult Total       | 32      |

**TABLE 38: CHARACTERISTICS OF PARTICIPANTS ACCORDING TO COUNTRY, MAIN DISCIPLINE OF CLINICAL PRACTICE, SCOPE OF PRACTICE AND EXPERTISE OF ASTHMA AND NFA ATTACKS WHO COMPLETED ALL THREE ROUNDS.**

| Expert number | Country        | Main discipline         | Paediatric | Adult | Clinician | Clinician and Academic | Asthma management expertise | Near-Fatal Asthma Attack expertise |
|---------------|----------------|-------------------------|------------|-------|-----------|------------------------|-----------------------------|------------------------------------|
| 002           | USA            | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 004           | Spain          | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 006           | USA            | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 007           | Turkey         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 009           | USA            | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 012           | Australia      | Critical Care           |            | ✓     | ✓         |                        | Slightly specialised (2)    | Quite specialised (4)              |
| 013           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Moderately specialised (3)  | Highly specialised (5)             |
| 015           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Moderately specialised (3)  | Quite specialised (4)              |
| 017           | New Zealand    | Critical Care           |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 018           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 020           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Slightly specialised (2)    | Quite specialised (4)              |
| 021           | Australia      | Critical Care           |            | ✓     | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 023           | New Zealand    | Critical Care           |            | ✓     | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 024           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 027           | Australia      | Critical Care           |            | ✓     |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 029           | New Zealand    | Critical Care           |            | ✓     | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 031           | Australia      | Critical Care           | ✓          |       | ✓         |                        | Moderately specialised (3)  | Quite specialised (4)              |
| 034           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 035           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 036           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 039           | New Zealand    | Critical Care           |            | ✓     |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |

| Expert number | Country        | Main discipline         | Paediatric | Adult | Clinician | Clinician and Academic | Asthma management expertise | Near-Fatal Asthma Attack expertise |
|---------------|----------------|-------------------------|------------|-------|-----------|------------------------|-----------------------------|------------------------------------|
| 040           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Slightly specialised (2)           |
| 042           | Portugal       | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 043           | Australia      | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 044           | Australia      | Emergency medicine      | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 045           | Australia      | Emergency medicine      | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 046           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 047           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 048           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 049           | Netherlands    | Critical Care           | ✓          |       |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 050           | Australia      | Emergency medicine      | ✓          |       | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 051           | Bulgaria       | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 052           | Romania        | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 053           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 054           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Quite specialised (4)       | General (1)                        |
| 055           | Brazil         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 059           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 060           | United Kingdom | Emergency medicine      | ✓          |       |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 061           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 062           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 063           | Canada         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 064           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 066           | Brazil         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Slightly specialised (2)           |
| 067           | United States  | Emergency medicine      | ✓          |       |           | ✓                      | Quite specialised (4)       | Highly specialised (5)             |
| 069           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Moderately specialised (3)  | Quite specialised (4)              |
| 070           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 072           | Singapore      | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |

| Expert number | Country        | Main discipline         | Paediatric | Adult | Clinician | Clinician and Academic | Asthma management expertise | Near-Fatal Asthma Attack expertise |
|---------------|----------------|-------------------------|------------|-------|-----------|------------------------|-----------------------------|------------------------------------|
| 073           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 074           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 075           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 076           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 079           | Spain          | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 080           | Czech Republic | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Slightly specialised (2)           |
| 081           | Spain          | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 087           | Germany        | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 088           | Russia         | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 089           | Romania        | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 091           | Russia         | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 094           | Croatia        | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 095           | Canada         | Emergency medicine      | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 097           | Spain          | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 099           | Portugal       | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 103           | Netherlands    | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 104           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 105           | Czech Republic | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Slightly specialised (2)           |
| 106           | Sweden         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 108           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Moderately specialised (3)         |
| 109           | Brazil         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Slightly specialised (2)           |
| 110           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Moderately specialised (3)  | Slightly specialised (2)           |
| 112           | Italy          | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 114           | Portugal       | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 116           | Brazil         | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 120           | Singapore      | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 122           | Albania        | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |



| Expert number | Country        | Main discipline         | Paediatric | Adult | Clinician | Clinician and Academic | Asthma management expertise | Near-Fatal Asthma Attack expertise |
|---------------|----------------|-------------------------|------------|-------|-----------|------------------------|-----------------------------|------------------------------------|
| 123           | Argentina      | Respiratory/pulmonology |            | ✓     | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 124           | Switzerland    | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 125           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 127           | United Kingdom | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 128           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 129           | South Africa   | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 130           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 132           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 133           | Netherlands    | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Moderately specialised (3)         |
| 134           | Canada         | Critical Care           | ✓          |       |           | ✓                      | Slightly specialised (2)    | Quite specialised (4)              |
| 135           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 138           | Canada         | Emergency medicine      | ✓          |       | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 140           | Australia      | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 142           | United Kingdom | Emergency medicine      | ✓          |       | ✓         |                        | Slightly specialised (2)    | General (1)                        |
| 143           | United Kingdom | Respiratory/pulmonology |            | ✓     |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 144           | United Kingdom | Critical Care           | ✓          |       | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 145           | Spain          | Critical Care           | ✓          |       | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 146           | Canada         | Emergency medicine      | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 147           | Ukraine        | Respiratory/pulmonology | ✓          |       |           | ✓                      | Quite specialised (4)       | Slightly specialised (2)           |
| 148           | Chile          | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Moderately specialised (3)         |
| 149           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Highly specialised (5)      | Quite specialised (4)              |
| 151           | United Kingdom | Emergency medicine      | ✓          |       | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |
| 152           | Netherlands    | Critical Care           | ✓          |       |           | ✓                      | Moderately specialised (3)  | Highly specialised (5)             |
| 153           | United Kingdom | Respiratory/pulmonology |            | ✓     | ✓         |                        | Quite specialised (4)       | Moderately specialised (3)         |
| 155           | Netherlands    | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 156           | United Kingdom | Emergency medicine      | ✓          |       | ✓         |                        | Quite specialised (4)       | Highly specialised (5)             |

| Expert number | Country        | Main discipline         | Paediatric | Adult | Clinician | Clinician and Academic | Asthma management expertise | Near-Fatal Asthma Attack expertise |
|---------------|----------------|-------------------------|------------|-------|-----------|------------------------|-----------------------------|------------------------------------|
| 157           | United Kingdom | Respiratory/pulmonology | ✓          |       | ✓         |                        | Moderately specialised (3)  | Slightly specialised (2)           |
| 159           | Netherlands    | Critical Care           | ✓          |       |           | ✓                      | Moderately specialised (3)  | Highly specialised (5)             |
| 160           | Netherlands    | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |
| 161           | Spain          | Respiratory/pulmonology | ✓          |       |           | ✓                      | Highly specialised (5)      | Quite specialised (4)              |

The largest group of consultants recruited were from paediatric respiratory, n=54/104 (52%) followed by adult respiratory, n=20/104 (19%). There was no representation from adult ED which was attributed to the inability to distribute via group lists. The participants were from a total of 25 countries (final round) with the highest representation from the United Kingdom, 37/104 (36%) (Figure 10). The countries were further analysed by continent and those living in Europe participated the most in the final round, 67/104 (64%) (Figure 11)<sup>6</sup>.

<sup>6</sup> All numbers have been rounded up to the nearest whole number.

FIGURE 10: NUMBER OF PARTICIPANTS BY COUNTRY ACROSS EACH ALL 3 ROUNDS OF EDELPHI

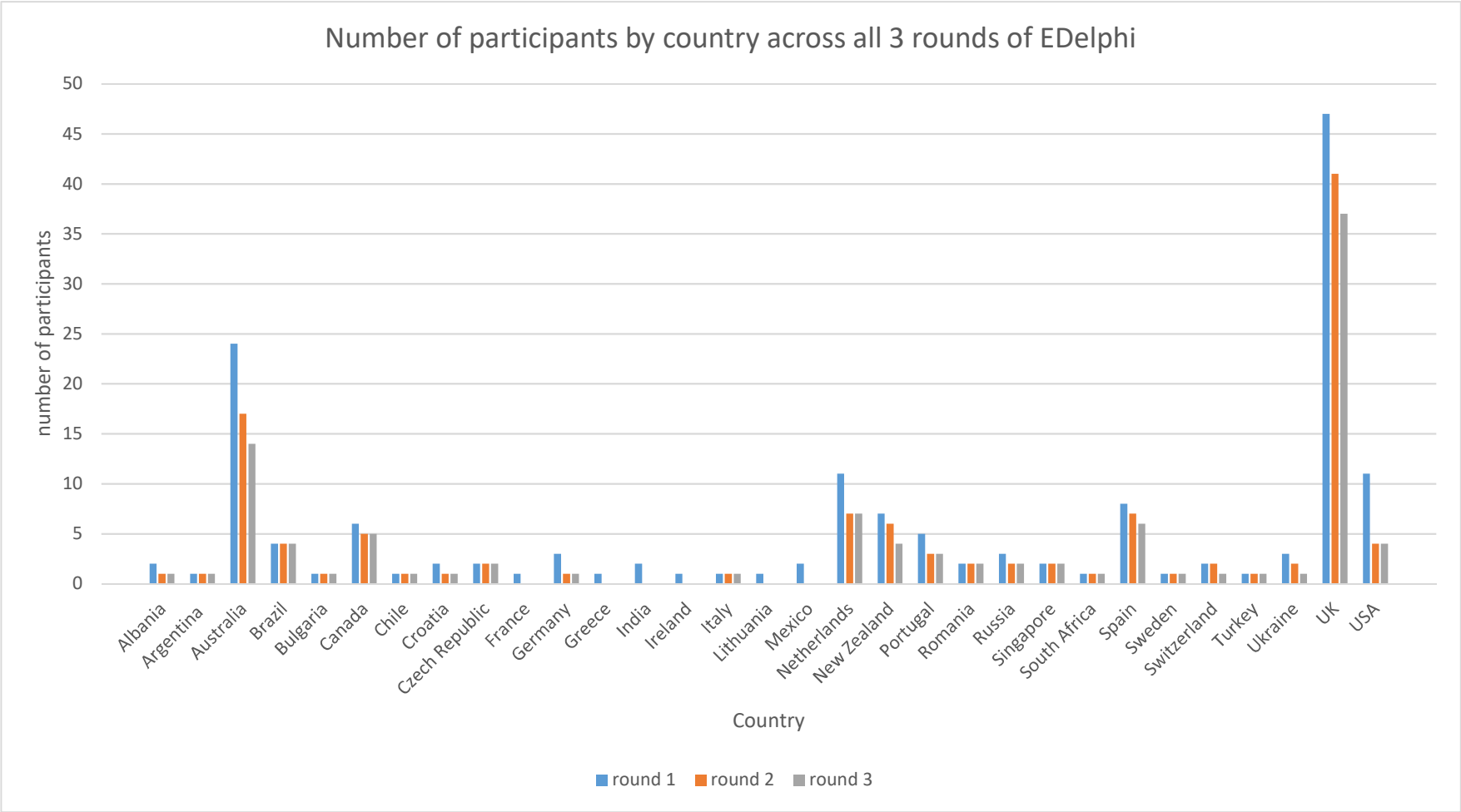
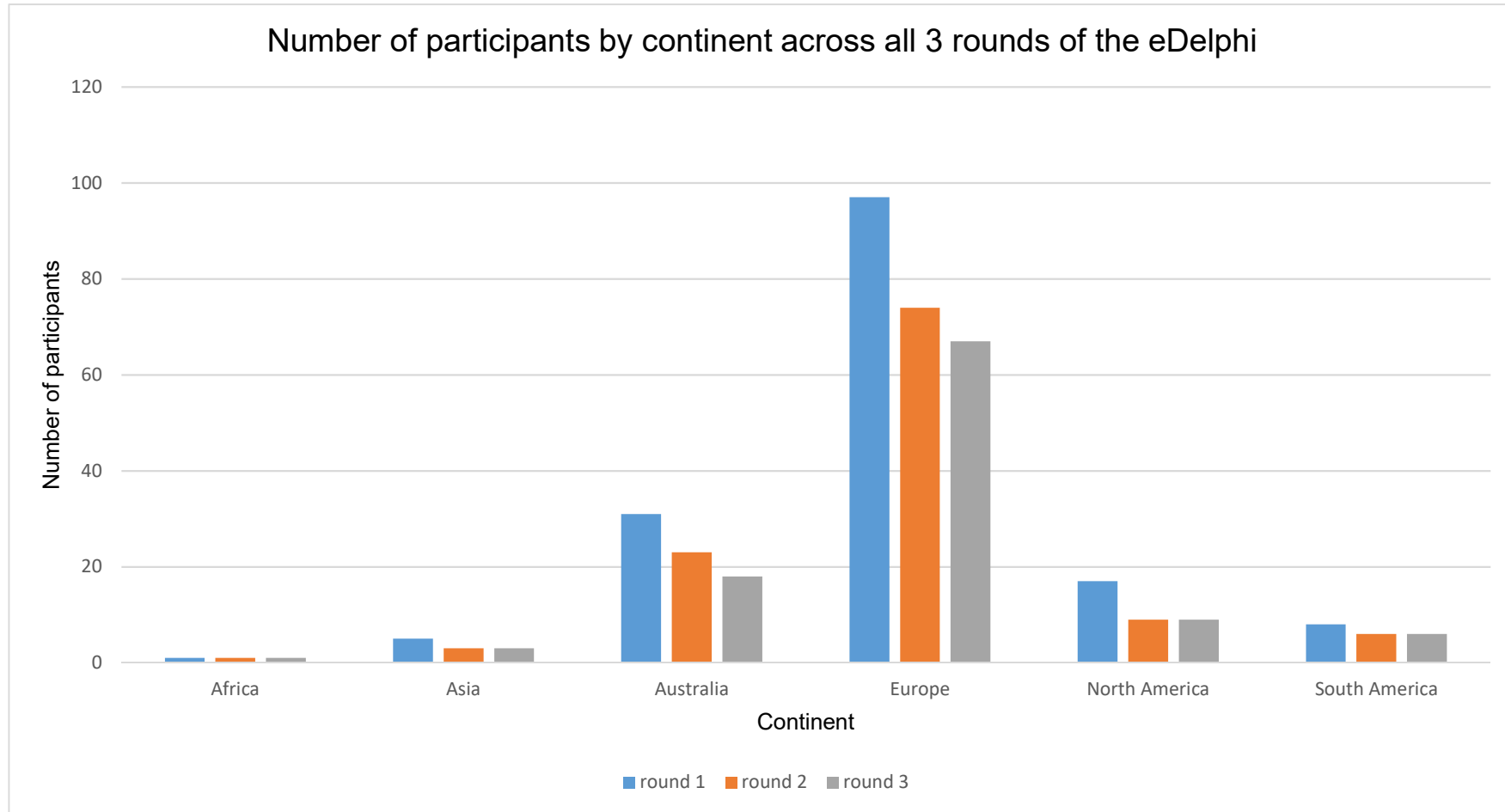
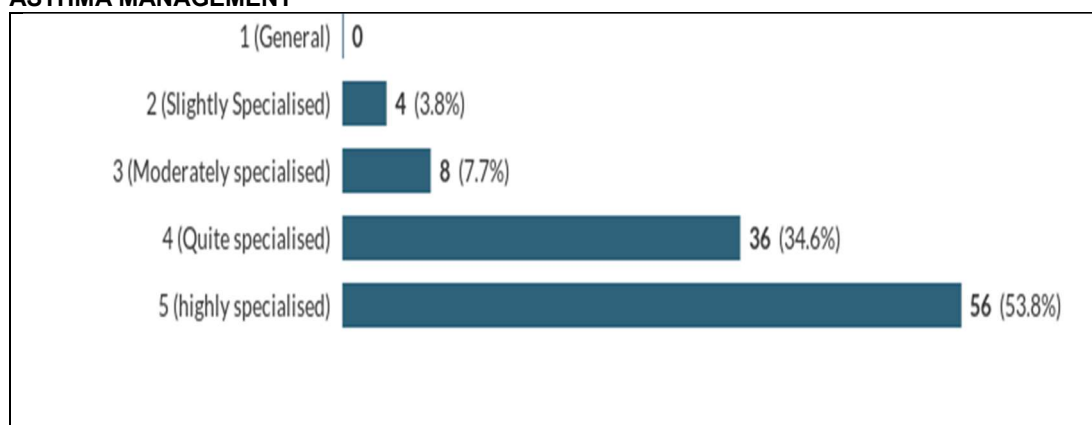


**FIGURE 11: NUMBER OF PARTICIPANTS BY CONTINENT ACROSS ALL 3 ROUNDS OF THE EDELPHI**



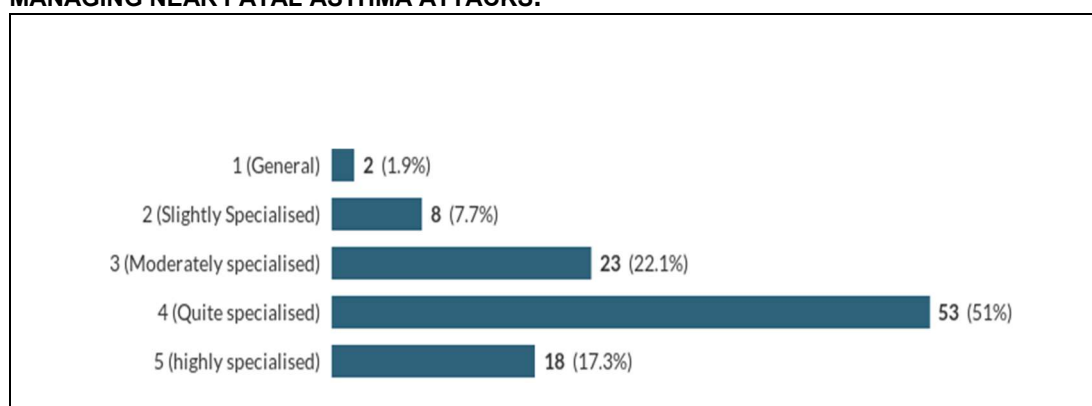
Participants also ranked their level of expertise using a Likert scale in the management of asthma and near fatal asthma attacks: highly specialised (5), quite specialised (4), moderately specialised (3), slightly specialised (2) and general (1). Ninety two (n=92/104, 88%) participants ranked their level of expertise in asthma as either highly specialised or quite specialised (Figure 12).

**FIGURE 12: DISTRIBUTION OF PARTICIPANTS ACCORDING TO SELF-RANKED EXPERTISE IN ASTHMA MANAGEMENT**



Seventy one (n=71/104, 68%) participants ranked their level of expertise in the management of a near fatal asthma attack as either highly specialised or quite specialised (Figure 13).

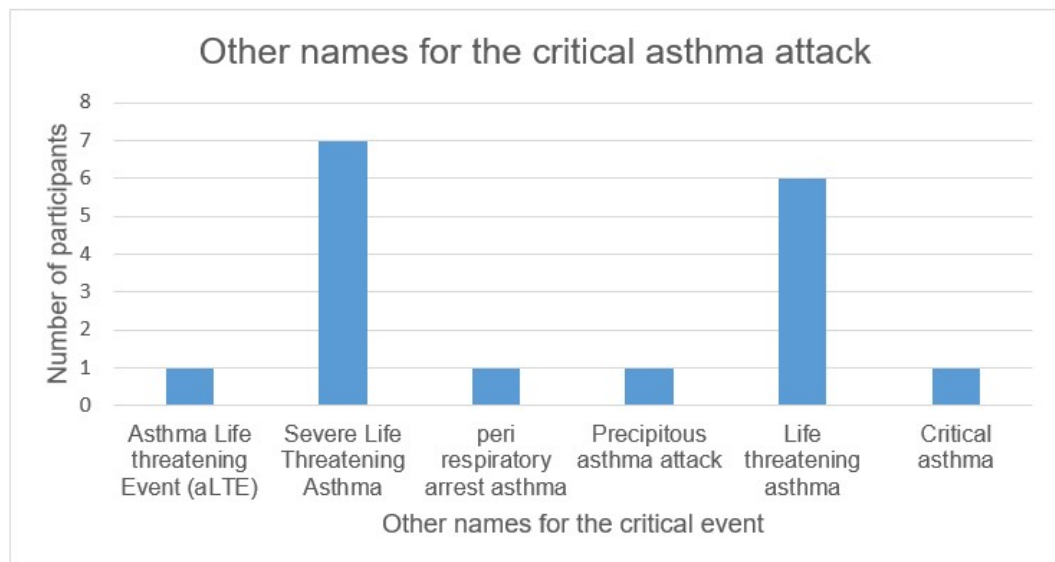
**FIGURE 13: DISTRIBUTION OF PARTICIPANTS ACCORDING TO SELF-RANKED EXPERTISE IN MANAGING NEAR FATAL ASTHMA ATTACKS.**



### 5.11 Round one results, name of the event

Participants did not reach consensus for a name in round one although there was a preference for near fatal asthma,  $n=60/159$  (38%). The free text 'other' option attracted further possible names,  $n=17/159$  (11%), (Figure 14), which included; asthma life threatening event,  $n=1/159$  (0.6%), severe life threatening asthma,  $n=7/159$  (4%), peri-respiratory arrest asthma,  $n=1/159$  (0.6%), precipitous asthma attack,  $n=1/159$  (0.6%), life threatening asthma,  $n=6/159$  (3.7%) and critical asthma,  $n=1/159$  (0.6%).

**Figure 14: Other names used by participants to describe a critical asthma attack**



### 5.12 Thematic analysis of free text data

Free text comments from participants were thematically analysed and provided the following themes: Interchangeable terminology, current understanding, impact of variables and emotive terminology.

### 5.12.1 Interchangeable terminology

Some of the participants commented on the use of a number of terms, often more than one name, to describe the attack, and admitted that status asthmaticus was out dated and required clarity.

*"I use "critical asthma" to denote asthma attacks requiring critical care, and Near-Fatal asthma when intubation/mechanical ventilation is needed."*

(037)

*"I might have chosen 'Status asthmaticus' however I worry that this term has been around a long time and already has a different meaning for many."*

(038)

A few participants were of the opinion that near fatal asthma was a retrospective term and could only be applied after the event had taken place.

*"status asthmaticus" describes asthma of a whole range of severity; "near fatal asthma" is a retrospective diagnosis."*

(014)

*"I like the term - I would have previously used NFA but NFA is a retrospective diagnosis so I prefer Critical Asthma syndrome."*

(140)

### 5.12.2 Current Understanding

A few of the participants believed that near fatal asthma was the preferred name as it was commonly used in literature and was indicative of asthma severity.

*"NFA is usually used in the literature."*

(097)

*"It indicates severity and the fact that this level of severity threatens life. It agrees with common terms accepted nowadays."*

(051)



### 5.12.3 Impact of variables

Some of the participants believed that other variables had an impact upon the name given to the event including circumstances, resources available and response to treatment.

*“Near fatal... depends on the circumstances, education, and resources available”*

(004)

*“The “life threatening” bit is often only apparent after non-response to/deterioration after the first hour’s nebs +/- iv aminophylline.”*

(040)

### 5.12.4 Emotive terminology

A couple of participants were concerned about the use of the term near fatal asthma and how this could negatively impact upon the person experiencing the event.

*“near fatal is unnecessarily emotive, the term will be overused. Most asthmatics don’t die even when peri arrest.”*

(029)

*“I think the term ‘near fatal asthma’ is anxiety provoking.”*

(104)

### 5.13 Round one results of other variables

Participants completed the sections under the headings outlined in section 5.8 and are presented in Table 39. Forty one variables were tested in round one. Of these, 14 variables achieved consensus (green) in the first round, 15 variables fell just below the level of consensus (amber) and 12 variables appeared to have been rejected by our expert panel (red).

**TABLE 39: RESULTS OF ROUND ONE OF THE EDELPHI**

| Item Number | Item                                  | Response n/N (missing data) | Combined unimportance (1&2) | Combined importance (4&5) | Median (range = 1-5) |
|-------------|---------------------------------------|-----------------------------|-----------------------------|---------------------------|----------------------|
| 3.1         | Cardiac arrest                        | 154/159                     | 27 (17.5)                   | 85 (55.2)                 | 4                    |
| 3.2         | Respiratory arrest                    | 157/ 159                    | 10 (6.4)                    | 124 (79)                  | 5                    |
| 3.3         | NIV                                   | 156/159                     | 24 (14.1)                   | 102 (65.4)                | 4                    |
| 3.4         | Invasive ventilation                  | 156/159                     | 4 (2.5)                     | 137 (87.8)                | 5                    |
| 3.5         | Hypoxic seizure                       | 153/159                     | 39 (25.5)                   | 76 (49.7)                 | 3                    |
| 4.1         | Silent chest                          | 158/159                     | 7 (4.5)                     | 121 (77.6)                | 4                    |
| 4.2         | Apnoeic episode                       | 154/159                     | 12 (7.8)                    | 99 (64.3)                 | 4                    |
| 4.3         | Sternocleidomuscle use                | 154/159                     | 20 (12.9)                   | 91 (59.1)                 | 4                    |
| 4.4         | Paradoxical Thoracoabdominal movement | 155/159                     | 20 (12.9)                   | 91 (59.1)                 | 4                    |
| 4.5         | Central cyanosis                      | 155/159                     | 12 (7.7)                    | 117 (75.5)                | 4                    |
| 4.6         | Unable to speak                       | 157/159                     | 6 (3.8)                     | 137 (87.3)                | 4                    |
| 4.7         | Unable to sleep                       | 153/159                     | 39 (25.5)                   | 65 (42.4)                 | 3                    |
| 4.8         | Need to sit upright                   | 155/159                     | 20 (12.9)                   | 90 (58.1)                 | 4                    |
| 4.9         | Unable to maintain posture            | 152/159                     | 23 (15.1)                   | 80 (52.6)                 | 4                    |
| 4.10        | Exhausted                             | 154/159                     | 9 (5.8)                     | 130 (84.4)                | 4                    |
| 4.11        | Severely agitated                     | 153/159                     | 16 (10.4)                   | 111 (72.5)                | 4                    |
| 4.12        | Confused                              | 156/159                     | 17 (10.9)                   | 106 (68)                  | 4                    |
| 4.13        | Severe dyspnoea                       | 155/159                     | 0                           | 132 (85.1)                | 5                    |
| 5.1         | Immeasurable PEFr                     | 152/159                     | 53 (34.9)                   | 53 (34.9)                 | 3                    |
| 5.2         | Tachycardia                           | 153/159                     | 18 (11.8)                   | 68 (44.5)                 | 3                    |
| 5.3         | Bradycardia                           | 151/159                     | 12 (7.9)                    | 102 (67.6)                | 4                    |
| 5.4         | SpO <sub>2</sub> <90%                 | 155/159                     | 8 (5.2)                     | 123 (79.3)                | 4                    |
| 5.5         | Increased RR                          | 152/159                     | 18 (11.8)                   | 83 (54.6)                 | 4                    |
| 5.6         | Decreased RR                          | 152/159                     | 9 (5.9)                     | 102 (67.1)                | 4                    |
| 5.7         | Cap refill > 2 secs                   | 155/159                     | 27 (17.4)                   | 71 (45.8)                 | 3                    |
| 5.8         | AVPU will be P or U                   | 153/159                     | 13 (8.5)                    | 111 (72.5)                | 4                    |
| 5.9         | Pulsus paradoxus                      | 153/159                     | 25 (16.3)                   | 75 (49.1)                 | 3                    |
| 5.10        | Hypotensive                           | 152/159                     | 21 (13.8)                   | 78 (51.4)                 | 4                    |
| 5.11        | pH value will fall                    | 153/159                     | 8 (5.3)                     | 120 (78.4)                | 4                    |
| 5.12        | PaO <sub>2</sub> will fall            | 155/159                     | 9 (5.8)                     | 128 (82.6)                | 4                    |
| 5.13        | PaCO <sub>2</sub> will rise           | 157/159                     | 4 (2.5)                     | 142 (90.4)                | 5                    |
| 5.14        | Lactate levels rise                   | 152/159                     | 16 (10.5)                   | 88 (57.9)                 | 4                    |
| 5.15        | CXR                                   | 154/159                     | 27 (17.5)                   | 79 (51.3)                 | 4                    |
| 6.1         | Air hunger                            | 154/159                     | 18 (11.6)                   | 82 (53.3)                 | 4                    |
| 6.2         | Go outside/ open window               | 151/159                     | 72 (47.7)                   | 23 (15.3)                 | 3                    |
| 6.3         | Steam                                 | 151/159                     | 100 (66.2)                  | 7 (4.6)                   | 2                    |
| 6.4         | Attack at night                       | 152/159                     | 61 (40.1)                   | 43 (28.3)                 | 3                    |
| 6.5         | Attack in the morning                 | 148/159                     | 70 (47.3)                   | 31 (21)                   | 3                    |

| Item Number                                                      | Item                          | Response n/N (missing data) | Combined unimportance (1&2) | Combined importance (4&5) | Median (range = 1-5)  |
|------------------------------------------------------------------|-------------------------------|-----------------------------|-----------------------------|---------------------------|-----------------------|
| 6.6                                                              | Seasonal                      | 150/159                     | 63 (42)                     | 35 (23.3)                 | 3                     |
| 6.7                                                              | Gut feeling                   | 155/159                     | 11 (7.1)                    | 109 (70.3)                | 4                     |
| 7.1                                                              | Adrenaline Autoinjector (AAI) | 159/159                     | 25 (15.7)                   | 75 (47.2)                 | 3                     |
| The colours used in the table represent the degree of consensus. |                               |                             |                             |                           |                       |
|                                                                  | Consensus $\geq 70\%$         |                             | Consensus 50% - 69%         |                           | Consensus $\leq 49\%$ |

Free text boxes were available for participants to add numerical values to the objective measurements and any other clinical features they felt were omitted. The numerical values given by participants are presented as Figures 15 to 25. These were added to the round two questionnaire. Values for the objective measurements did not reach consensus with a varied range of responses from the participants.

**FIGURE 15: PEAK FLOW VALUES (% PREDICTED)**  
N=6/159

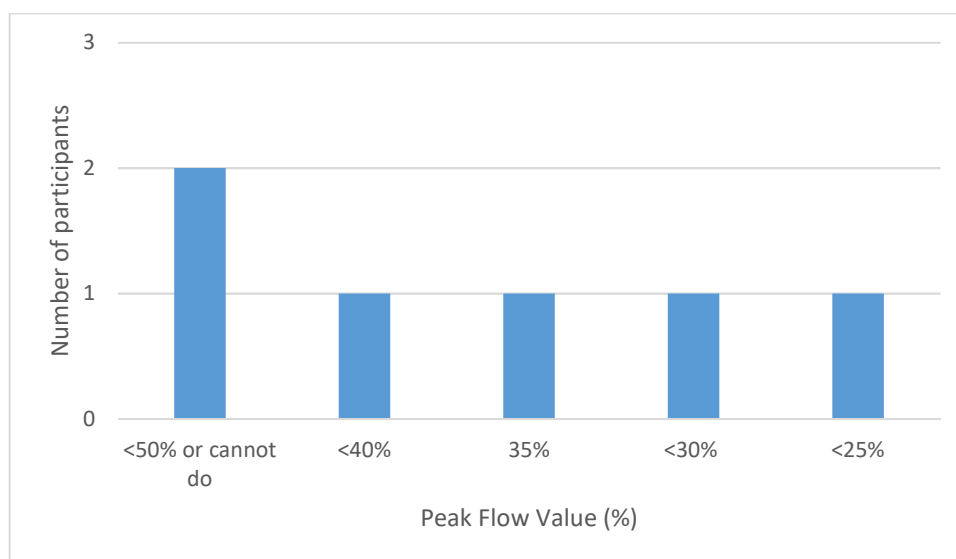


**FIGURE 16: HEART RATE (BPM)**  
N=50/159

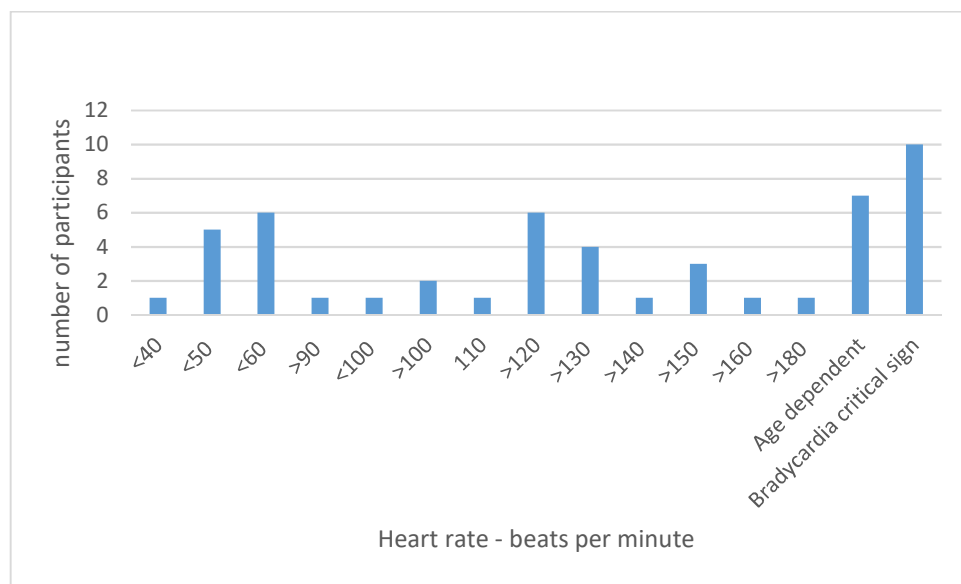


**FIGURE 17: OXYGEN SATURATION (%)**  
N=43/159

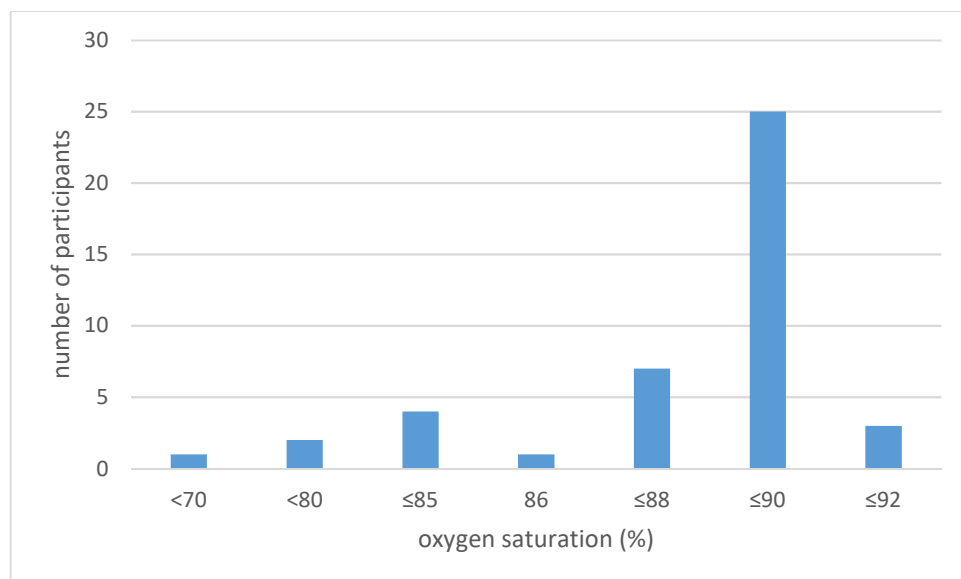


**FIGURE 18: RESPIRATORY RATE (PER MINUTE)**  
N=47/159

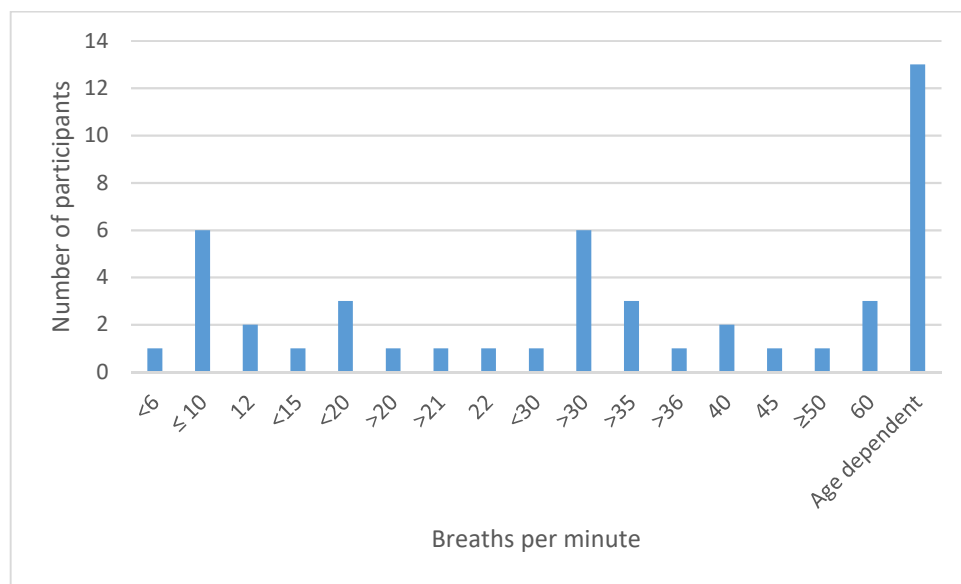


**FIGURE 19: CAPILLARY REFILL (SECONDS)**  
N=17/159

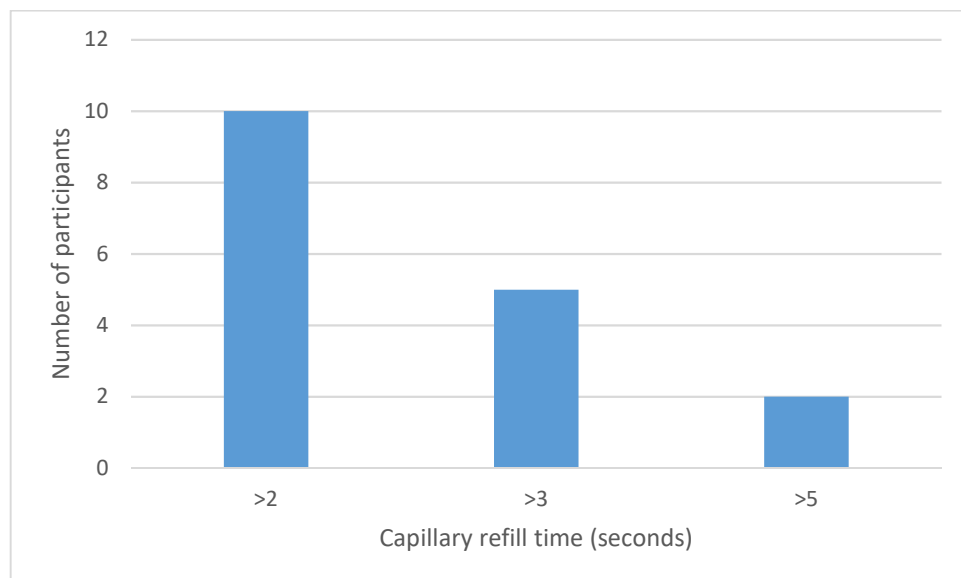


**FIGURE 20: AVPU (ALERT, VERBAL, PAIN, UNRESPONSIVE) VALUES**  
N=18/159

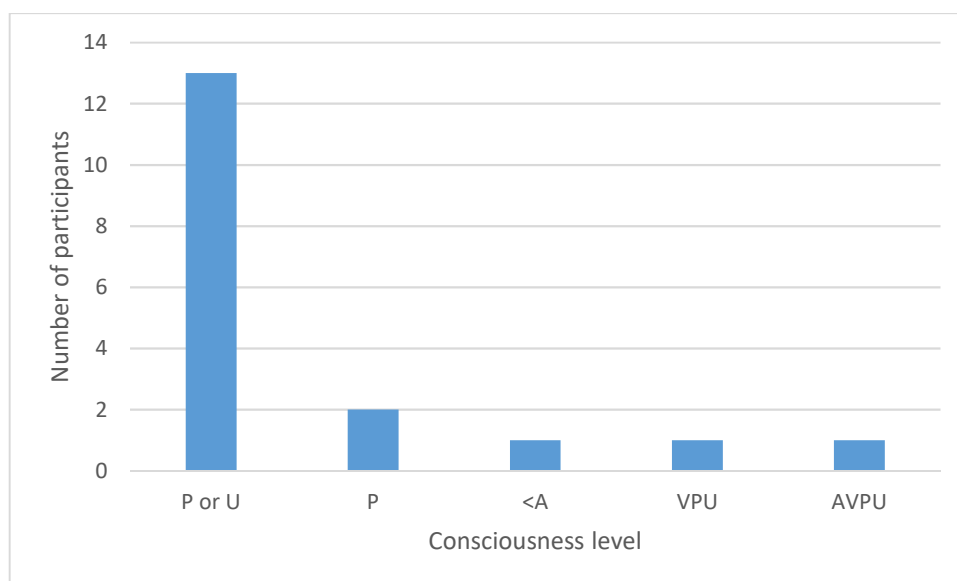


**FIGURE 21: PH VALUES**  
N=36/159

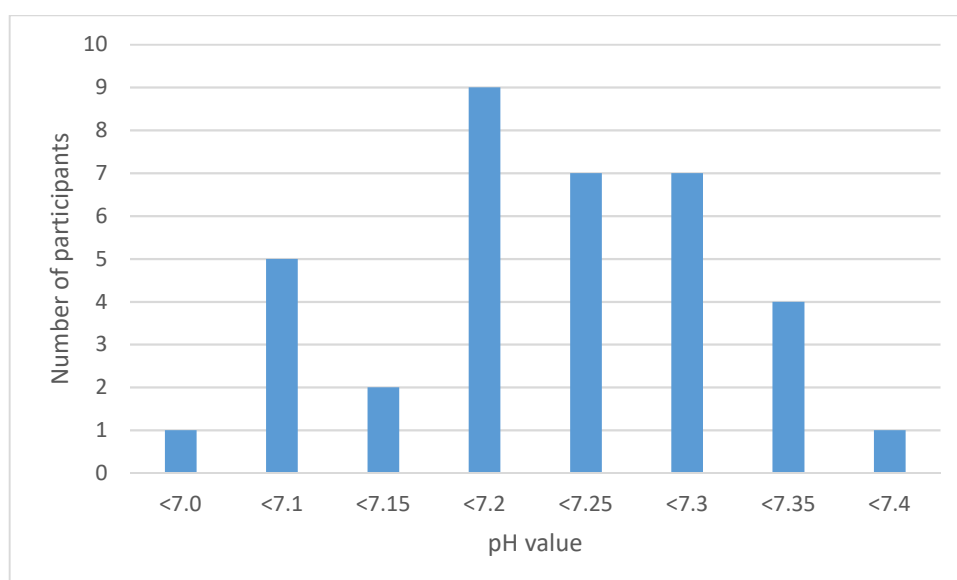


**Figure 22: Pulsus Paradoxus (mmHg) values**  
N=9/159

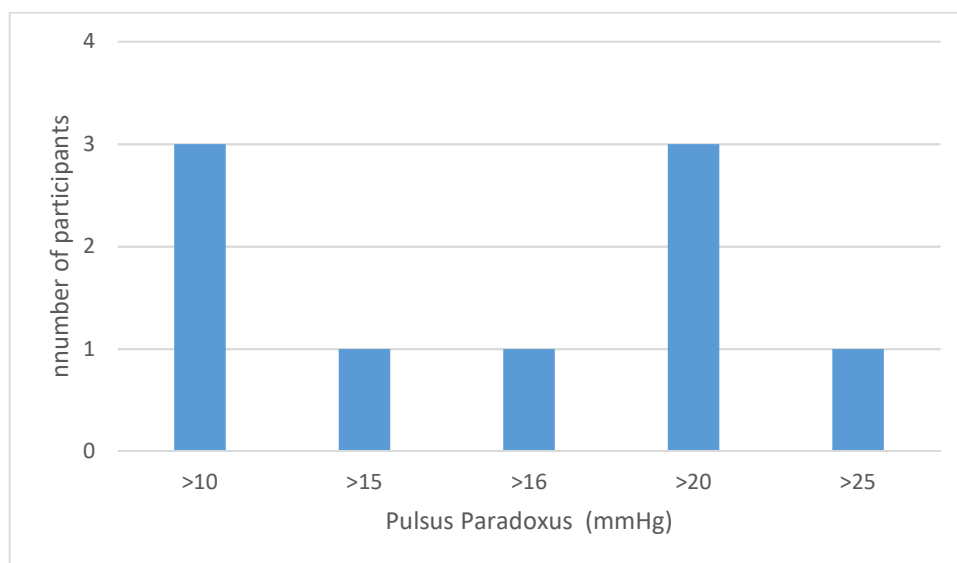


**FIGURE 23: PAO<sub>2</sub> (MMHG) VALUES**  
N=34/159

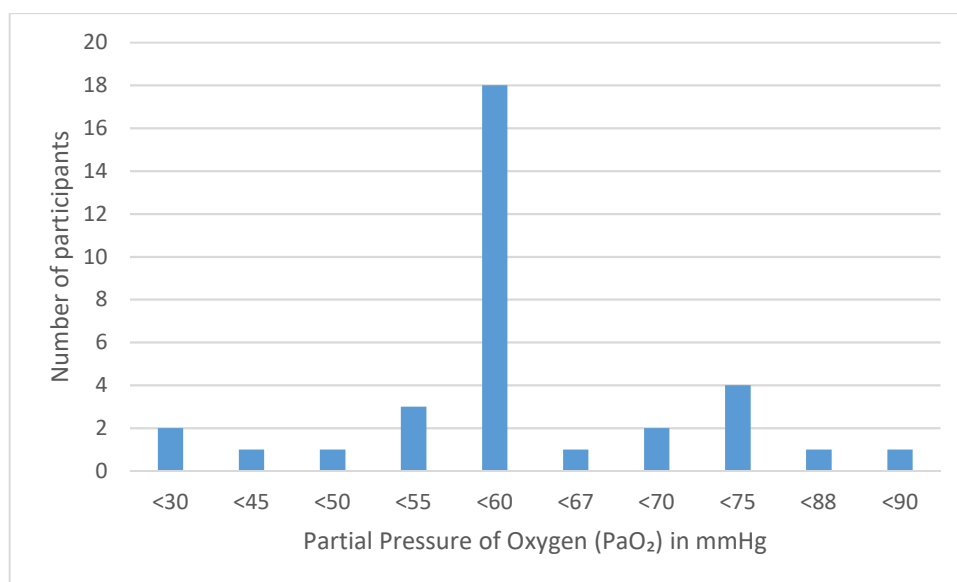


**Figure 24: PaCO<sub>2</sub> (mmHg) values**  
N=44/159

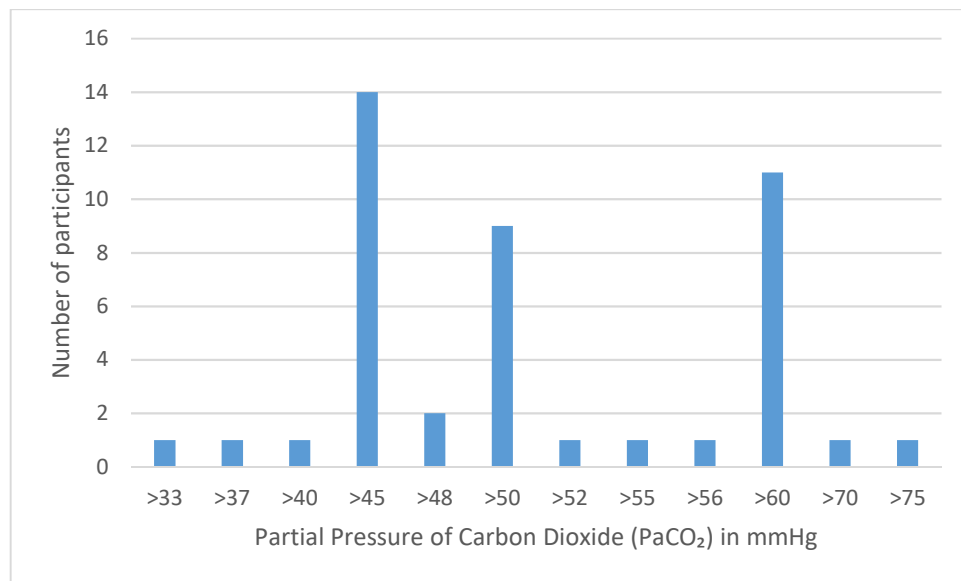
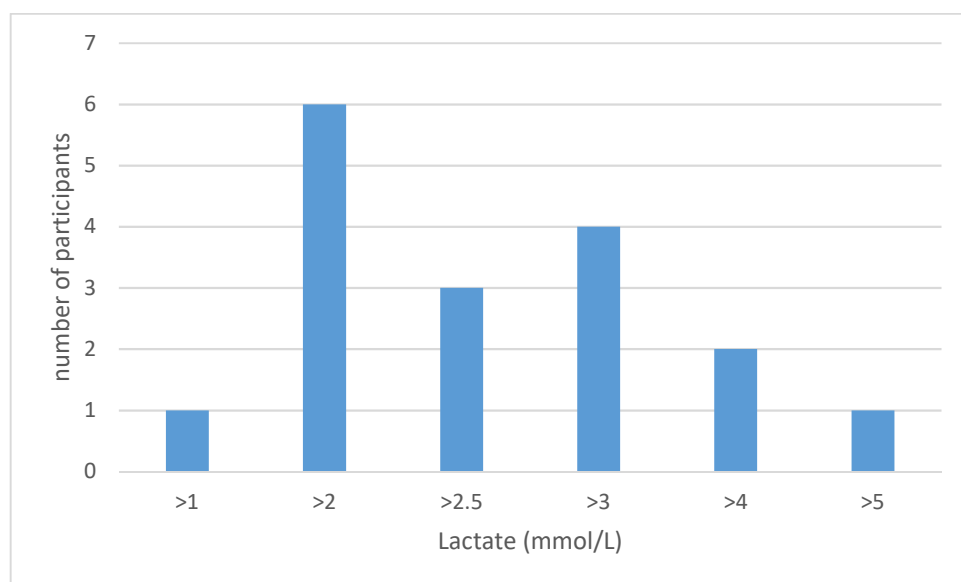


**FIGURE 25: LACTATE (MMOL/L) VALUES**  
N=17/159





Participants also added some additional features they believed were in keeping with this attack as free text responses within the 'other' category. They included excessive use of salbutamol (n=2/159), unable to cooperate with care (n=1/159), not responding to emergency treatment (n=1/159), extreme anxiety (n=1/159), a sense of doom (n=1/159) and feeling their asthma was out of control (n=1/159).

#### **5.14 Round two results**

One hundred and sixteen participants completed round two. Participants were unable to agree, with consensus, the name for the attack although near fatal asthma remained the preference n=65/116 (56%). The other names which participants felt described the attack were; severe life threatening asthma n=25/116 (22%), severe life threatening asthma with progressive respiratory failure n=18/116 (15%), status asthmaticus n=7/116 (6%) and precipitous asthma attack n=1/116 (1%). Participant free text contributions to round one, added a further seven variables to round two. Forty eight variables were tested in round two. Of these, 18 variables (an additional 7) achieved consensus (green), 18 fell just below consensus (amber) and 12 were rejected by our experts (red) (Table 40)

**TABLE 40: RESULTS OF ROUND TWO EDELPHI**

| Item Number | Item                                  | Response n/N (missing data) | Combined unimportance (1&2) | Combined importance (4&5) | Median score (range = 1-5) |
|-------------|---------------------------------------|-----------------------------|-----------------------------|---------------------------|----------------------------|
| 3.1         | Cardiac arrest                        | 115/116                     | 20 (17.4)                   | 65 (56.5)                 | 4                          |
| 3.2         | Imminent cardiac arrest               | 116/116                     | 8 (6.9)                     | 89 (76.8)                 | 4                          |
| 3.3         | Respiratory arrest                    | 114/116                     | 7 (6.1)                     | 92 (80.7)                 | 4                          |
| 3.4         | Imminent respiratory arrest           | 116/116                     | 1 (0.9)                     | 110 (94.9)                | 5                          |
| 3.5         | Invasive ventilation                  | 116/116                     | 4 (3.4)                     | 102 (87.9)                | 5                          |
| 3.6         | Hypoxic seizure                       | 112/116                     | 29 (25.9)                   | 57 (50.9)                 | 4                          |
| 3.7         | NIV                                   | 115/116                     | 15 (13)                     | 68 (59.1)                 | 4                          |
| 4.1         | Silent chest                          | 116/116                     | 5 (4.3)                     | 95 (81.9)                 | 4                          |
| 4.2         | Apnoeic episode                       | 116/116                     | 13 (11.2)                   | 78 (67.3)                 | 4                          |
| 4.3         | Sternocleidomuscle use                | 116/116                     | 14 (12.1)                   | 69 (59.5)                 | 4                          |
| 4.4         | Paradoxical Thoracoabdominal movement | 116/116                     | 12 (10.4)                   | 66 (56.9)                 | 4                          |
| 4.5         | Central cyanosis                      | 116/116                     | 5 (4.3)                     | 97 (83.6)                 | 4                          |
| 4.6         | Unable to speak                       | 116/116                     | 1 (0.9)                     | 105 (90.6)                | 4                          |
| 4.7         | Unable to sleep                       | 116/116                     | 23 (19.8)                   | 53 (45.7)                 | 3                          |
| 4.8         | Need to sit upright                   | 116/116                     | 14 (12)                     | 69 (59.5)                 | 4                          |
| 4.9         | Unable to maintain posture            | 116/116                     | 17 (14.6)                   | 61 (52.6)                 | 4                          |
| 4.10        | Exhausted                             | 116/116                     | 2 (1.7)                     | 101 (87.1)                | 4                          |
| 4.11        | Severely agitated                     | 116/116                     | 5 (4.3)                     | 89 (76.8)                 | 4                          |
| 4.12        | Confused                              | 116/ 116                    | 8 (6.9)                     | 78 (67.2)                 | 4                          |
| 4.13        | Severe dyspnoea                       | 116/116                     | 1 (0.9)                     | 103 (88.8)                | 5                          |
| 5.1         | Immeasurable PEFR                     | 116/116                     | 37 (31.9)                   | 44 (37.9)                 | 3                          |
| 5.2         | Tachycardia                           | 116/116                     | 21 (18.1)                   | 57 (49.1)                 | 3                          |
| 5.3         | Bradycardia                           | 116/116                     | 9 (7.7)                     | 76 (65.6)                 | 4                          |
| 5.4         | SpO <sub>2</sub> <90%                 | 116/116                     | 3 (2.6)                     | 99 (85.4)                 | 4                          |
| 5.5         | Increased RR                          | 116/116                     | 20 (17.2)                   | 65 (56)                   | 4                          |
| 5.6         | Decreased RR                          | 116/116                     | 8 (6.9)                     | 69 (59.5)                 | 4                          |
| 5.7         | Cap refill > 2 secs                   | 116/116                     | 26 (22.4)                   | 69 (59.5)                 | 3                          |
| 5.8         | AVPU will be P or U                   | 116/116                     | 7 (6.1)                     | 88 (75.9)                 | 4                          |
| 5.9         | Pulsus paradoxus                      | 116/116                     | 25 (21.5)                   | 53 (45.7)                 | 3                          |
| 5.10        | Hypotensive                           | 116/116                     | 16 (13.8)                   | 54 (46.5)                 | 3                          |
| 5.11        | pH value will fall                    | 116/116                     | 5 (4.3)                     | 96 (82.8)                 | 4                          |
| 5.12        | PaO <sub>2</sub> will fall            | 116/116                     | 8 (6.9)                     | 97 (83.6)                 | 4                          |
| 5.13        | PaCO <sub>2</sub> will rise           | 116/116                     | 3 (2.6)                     | 111 (95.7)                | 5                          |
| 5.14        | Lactate levels rise                   | 116/116                     | 16 (13.8)                   | 74 (63.8)                 | 4                          |
| 5.15        | CXR                                   | 116/116                     | 26 (22.4)                   | 54 (46.6)                 | 3                          |
| 6.1         | Air hunger                            | 116/116                     | 11 (9.5)                    | 68 (58.6)                 | 4                          |

| Item Number | Item                            | Response n/N (missing data) | Combined unimportance (1&2) | Combined importance (4&5) | Median score (range = 1-5) |
|-------------|---------------------------------|-----------------------------|-----------------------------|---------------------------|----------------------------|
| 6.2         | Go outside/ open window         | 116/116                     | 3 (2.6)                     | 16 (13.8)                 | 3                          |
| 6.3         | Steam                           | 116/116                     | 75 (64.7)                   | 4 (3.4)                   | 2                          |
| 6.4         | Attack at night                 | 116/116                     | 47 (40.5)                   | 21 (18.1)                 | 3                          |
| 6.5         | Attack in the morning           | 116/116                     | 51 (44)                     | 11 (9.5)                  | 3                          |
| 6.6         | Excessive salbutamol use        | 116/116                     | 51 (44)                     | 67 (57.7)                 | 4                          |
| 6.7         | Seasonal                        | 116/116                     | 39 (33.6)                   | 18 (15.5)                 | 3                          |
| 6.8         | uncooperative                   | 116/116                     | 11 (0.9)                    | 59 (50.9)                 | 4                          |
| 6.9         | Gut feeling                     | 116/116                     | 7 (6.1)                     | 87 (75)                   | 4                          |
| 6.10        | Extremely anxious               | 116/116                     | 5 (4.3)                     | 84 (72.4)                 | 4                          |
| 6.11        | Asthma 'out of control'         | 116/116                     | 13 (11.2)                   | 70 (60.4)                 | 4                          |
| 6.12        | Not responding to emergency AAP | 116/116                     | 5 (4.3)                     | 84 (72.4)                 | 4                          |
| 7.1         | AAI (had NFA)                   | 116/116                     | 18 (15.5)                   | 68 (58.6)                 | 4                          |
| 7.2         | AAI (at risk of NFA)            | 112/116                     | 27 (24.1)                   | 44 (39.3)                 | 3                          |
|             | Consensus $\geq 70\%$           |                             | Consensus 50% - 69%         |                           | Consensus $\leq 49\%$      |

Actual values for objective measurements did not achieve consensus despite fewer options. There was however consensus that oxygen saturations ( $\text{SpO}_2$ ) would be  $<90\%$ ,  $n=99/116$ , (85%), falling partial pressure of oxygen ( $\text{PaO}_2$ ),  $n=97/116$  (84%), rising arterial partial pressure of carbon dioxide ( $\text{PaCO}_2$ ),  $n=111/116$  (96%), falling pH value,  $n=96/116$  (83%) and AVPU (Alert, Verbal, Pain, Unresponsive – a scale of consciousness) will be P or U,  $n=88/116$  (76%), were of importance.

### 5.15 Round three results

One hundred and four participants completed round three. In the third and final round participants chose between near fatal asthma  $n=70/104$  (67%) and severe life threatening asthma,  $n=34/104$  (32%) as the name for the event with the former achieving preference.

As a research team, we discussed how to incorporate the consensus features from rounds one and two, into a working definition of NFA. Although I produced my own

version of what this definition may have looked like, we all agreed that Steve Cunningham's idea of providing a stem of a definition was the best approach. Participants were provided with a stem of a definition which could act as a stand-alone definition but with options for it to be refined with optional add on's (Table 41). The survey provided participants with the ability to choose from options A, A & B, A& C or A, B & C.

**TABLE 41: DEFINITION OF NEAR-FATAL ASTHMA STEM.**

| Definition(s) option | Definition(s)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| A                    | A 'critical asthma attack' occurs in a person who is exhausted, with severe dyspnoea, unable to speak with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies.                                                                                                                                                                                                                                                                                                                          |
| A & B                | A 'critical asthma attack' occurs in a person who is exhausted, with severe dyspnoea, unable to speak with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies. A 'critical asthma attack' is associated with hypoxaemia (value if consensus), with hypercarbia (value if consensus) and a falling pH (value if consensus)                                                                                                                                                               |
| A & C                | A 'critical asthma attack' occurs in a person who is exhausted, with severe dyspnoea, unable to speak with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies. A person experiencing a 'critical asthma event' will have a 'gut feeling' of the severity of their situation, be severely agitated and extremely anxious.                                                                                                                                                                |
| A, B & C             | A 'critical asthma attack' occurs in a person who is exhausted, with severe dyspnoea, unable to speak with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies. A 'critical asthma event' is associated with hypoxaemia (value if consensus), with hypercarbia (value if consensus) and a falling pH (value if consensus). A person experiencing a 'critical asthma attack' will be have a 'gut feeling' of the severity of their situation, be severely agitated and extremely anxious. |

Consensus was achieved with option A& B, n=83/104 (80%) (Table 42).

**TABLE 42: RESULTS OF OPTIONS PROVIDED FOR DEFINITION OF NEAR FATAL ASTHMA.**

| Item number | Item             | Response n/N (missing data) | 4 (most preferred) | Combined Lest preferred (1&2) (%) | Combined most preferred (3&4) (%) | Median (range = 1-4) |
|-------------|------------------|-----------------------------|--------------------|-----------------------------------|-----------------------------------|----------------------|
| 6.1         | Option A         | 104/104                     | 23 (22.1)          | 56 (53.8)                         | 48 (46.1)                         | 2                    |
| 6.2         | Options A & B    | 104/104                     | 40 (38.5)          | 21 (20.2)                         | 83 (79.8)                         | 3                    |
| 6.3         | Options A & C    | 104/104                     | 5 (4.8)            | 84 (80.8)                         | 20 (19.2)                         | 2                    |
| 6.4         | Options A, B & C | 104/104                     | 36 (34.6)          | 47 (45.2)                         | 57 (54.8)                         | 3                    |

Participants were unable to achieve consensus on two values for the objective measurements which were perceived to be of importance ( $\text{SpO}_2$  and  $\text{PaCO}_2$ ) however there was a preference for the following values:  $\text{SpO}_2 < 85\%$ ,  $n=58/104$  (56%) and  $\text{PaCO}_2 > 60\text{mmHg}/8\text{kPa}$ ,  $n=60/104$  (58%). Consensus was achieved on the pH value  $< 7.2$ ,  $n=74/104$  (71%).

#### **5.15.1 Sub-analysis of objective measurements**

I carried out a sub analysis on the preferred values for both  $\text{SpO}_2$  and  $\text{PaCO}_2$  within a sub group of experts,  $n=71/104$  (68%), who self-ranked their knowledge on managing near fatal asthma attacks as 'highly' or 'quite specialised' as they would most likely be the decision makers in determining what values they believed would be indicative of a near fatal attack. They did not reach consensus on either values however preferred  $\text{SpO}_2$  of  $< 85\%$ ,  $n=39/71$  (55%) (Figure 26) and  $\text{PaCO}_2$  of  $> 60\text{mmHg}/8\text{kPa}$ ,  $n=42/71$  (59%) (Figure 27).

**FIGURE 26: HIGHLY AND QUITE SPECIALISED EXPERTS PREFERRED VALUE FOR  $\text{SpO}_2$  (NFA attack)**

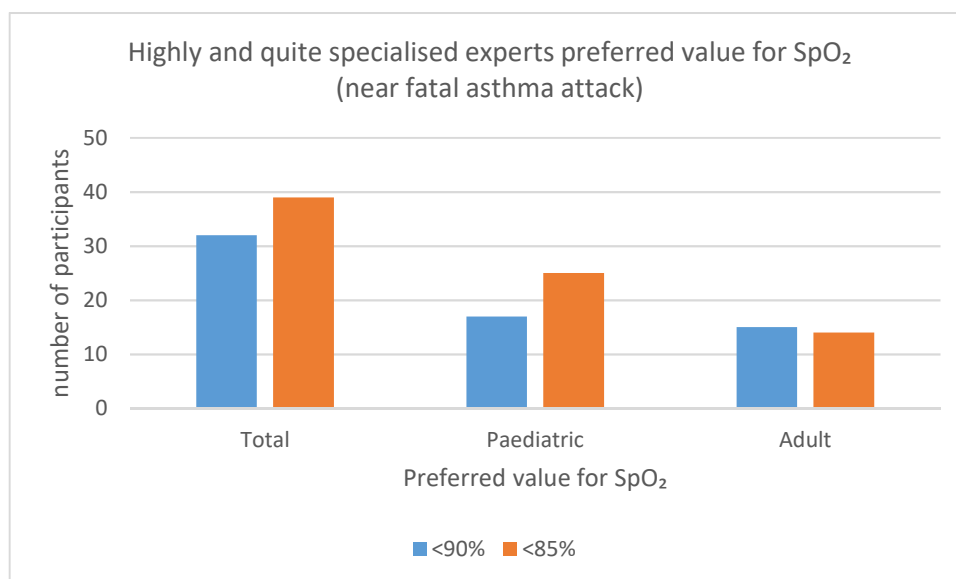
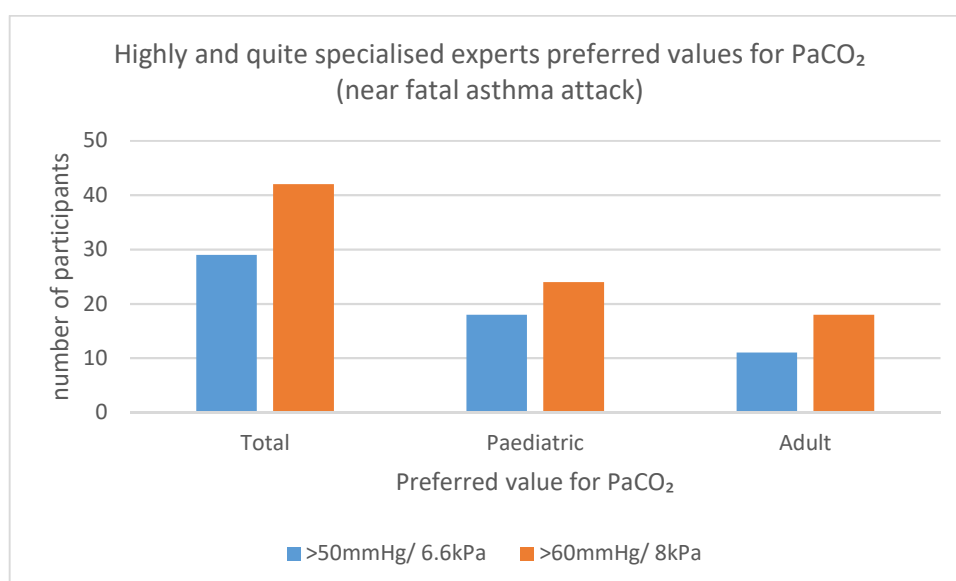


**FIGURE 27: HIGHLY AND QUITE SPECIALISED EXPERTS PREFERRED VALUE FOR  $\text{PaCO}_2$  (NFA attack)**



## 5.16 Discussion

To our knowledge, this is the first international consensus to determine a name and definition of near fatal asthma, a condition which is discussed within current literature

but acknowledged as poorly defined (Mitchell et al., 2002). The eDelphi identified consensus for 18 of 47 characteristics and this supported the development of a case definition which reached consensus by 80% of participants. The range of specialty of participants and their geographical distribution provide this name and definition with good generalisability across jurisdictions. Defining this type of attack from other severe attacks will enable clinicians and researchers to better understand the event frequency, the characteristics of those affected, and to support interventions that may improve outcomes. Additional management choices may include the use of anaesthetic gases or extracorporeal membrane oxygenation (ECMO), in association with traditional therapies such as intravenous aminophylline or magnesium sulphate (Schutte et al., 2013, Di Lascio et al., 2017). Patients who experience a NFA attack are deemed to have difficult asthma and therefore require long term follow (BTS/SIGN 2019). The British Guideline on the Management of Asthma does not differentiate between adults and children in this guidance therefore the reader could assume it applies to both groups. This definition should now be incorporated within guidelines to identify people with asthma who should have long term specialised follow up. Having a definition of NFA could enable collection of data on children who experience this event and could provide an incidence of how frequently these attacks occur. The current care they receive could be mapped and recommendations could be made on the care needs of this group to reduce the risks of a future NFA attack or asthma death.

Our expert panel of participants were asked to consider clinical features, objective measurements and other features, some of which were anecdotal, when considering what made this event different from a severe attack. Participants preferred to place importance on factors which would have been presented in academic journals and less emphasis on factors lacking an evidence base which included seasonal impact and the provision of an adrenaline auto injector post NFA. We would hope to add

further patient perspectives through a patient eDelphi to provide an addendum to this clinician derived eDelphi.

### **5.17 Strengths and limitations of the study**

The eDelphi panel of participants included clinical and academic experts within the fields of respiratory, emergency and critical care medicine, ensuring those who manage children, young people and young adults with NFA attacks, had an opportunity to contribute to this study. The majority of participants were highly specialised in the management of asthma, with relevant experience in managing near fatal events. Whilst there was a lack of representation of adult ED physicians in survey responses, emergency medicine training programmes in the UK, Australia and North America require completion of training across all age groups, and therefore those with paediatric ED expertise,  $n=11/104$  (10%), would be able to apply their knowledge across the targeted population of this study.

The ideal number of participants within a Delphi study is often debated, with no definitive answer. It has been noted that various panel sizes have been utilised within healthcare research with numbers ranging from 4 to 300 (Cantrill et al., 1996). The most frequently published sample sizes are between 10 to 100 experts, with the higher panel numbers used when the condition is more common, hence there will be a greater pool of experts (Akins et al., 2005). This study had 104 responses to all three rounds of the survey, which is toward the upper end of the sample size in previous studies, and is of value as the survey spanned specialties, age ranges and countries. Although we had representation from 23 countries the participation from the UK was much greater in comparison to other countries, especially North America which was likely to be attributed to the willingness of groups and societies distributing to members. From the outset of the eDelphi study I was aware that the response rate from all the methods used to recruit experts was unpredictable. Personally directed



email invitations yielded responses from 13 participants ( $n=13/153$ , 8%) and it is difficult to know if they would have responded, had they received a group invitation. A poor response rate from personally directed emails also helped to reinforce the decision to choose an open invitation as opposed to purposive sampling. We had discussed conducting the eDelphi study within the UK however the scoping review revealed the majority of authors in this area were based in North America and Europe. Overall, participation in the study achieved a good response rate (104 respondents) with a geographically diverse group which should assist in the acceptance of this definition in various asthma guidelines and future studies. We also utilised a previously applied technique to achieve consensus on a definition, when no gold standard exists (Simon et al., 2014). The study was conducted in English only. As a team we appreciated that language may have been a barrier to participation and some key experts in this field may have chosen not to take part as we did not offer a translated version. We were however time limited and had budget constraints.

Attrition is expected in a Delphi study, especially in the final round (McKenna, 1994). Although there is no agreed attrition (drop out) rate, there is a recommendation of 70% retention for each round to maintain rigor (Walker and Selfe, 1996). In this study although we had an overall retention rate of 65% ( $n=104/159$ ) between the first and third rounds, the rate between each round is as follows: Round One  $n=159$ , Round Two  $n=116/159$  (73%) and Round Three  $n=104/116$  (89%), thereby remaining above the recommended attrition rate of 70% between each round.

A comparison with other international eDelphi studies is shown in Table 43. Two of these studies had been conducted by members of AUKCAR, Dr Phyllis Murphie (former PhD student) and Professor Pinnock (Murphie et al., 2018, Pinnock et al., 2019).

**Table 43: A comparison of eDelphi studies considering participation, number of countries represented, number of rounds and % attrition rate.**

| <b>Delphi study</b>                                                   | <b>Number of Participants</b> | <b>Number of countries represented</b>    | <b>Number of rounds</b> | <b>Attrition rate between first and final round</b> |
|-----------------------------------------------------------------------|-------------------------------|-------------------------------------------|-------------------------|-----------------------------------------------------|
| Episodic breathlessness (Simon et al., 2014)                          | 31                            | 6                                         | 3                       | 0                                                   |
| Paratonia (Hobbelen et al., 2006)                                     | 8                             | 4                                         | 4                       | 0                                                   |
| Refractory neuropathic pain (Smith et al., 2012)                      | 25                            | 11                                        | 3                       | 24%                                                 |
| Osteoarthritis on MRI Hunter et al., 2011)                            | 16                            | 5                                         | 3                       | Not reported                                        |
| Clinical criteria for septic shock (Shankar-Hari et al., 2016)        | 19                            | Europe (number of countries not reported) | 3                       | Not reported                                        |
| Severe asthma registry (Bulathsinhala et al., 2019)                   | 27                            | 15                                        | 3                       | 38%                                                 |
| Clinical review of people using CPAP (Murphie et al., 2018)           | 47                            | 21                                        | 3                       | 15%                                                 |
| Standards for reporting implementation studies (Pinnock et al., 2017) | 23                            | 5                                         | 3                       | 17%                                                 |
| This study                                                            | 104                           | 23                                        | 3                       | 35%                                                 |

In comparison with these studies, we had a higher number of experts and number of countries represented than any of the other studies. The number of rounds in the majority of the studies was three. Percentage fall out was not always reported. The

attrition rate in this study was higher than most of their reported attrition rates but similar to Bulathsinhala et al. (2019). It is however of note that this study incorporated a significantly higher round one participant level and consequently attrition rates were broadly as anticipated. There was no clear pattern of participants who did not complete all three rounds in relation to speciality or continent. Those studies with zero attrition rates had included members of the panel as authors on the paper. Although this was not offered with our study, we agreed to acknowledge the experts' participation in a publication.

The scenario we set to initially describe the event, was also rather vague, however, this was deliberate, as we did not want to introduce bias on our perception of what a near-fatal attack looked like. This was open to interpretation by participants and may have caused some confusion for participants who did not speak English as their first language. We were also mindful of the resources available to treat near-fatal attacks in other countries however this eDelphi did not seek to gain consensus on medical management of this type of attack. We considered extending the panel to include nurse specialists and patients. Through discussion, the research team agreed that the knowledge and autonomy of nurses differs between countries and they would be unlikely to lead on decision making during a near-fatal asthma attack. We decided not to include patients, as they may not be aware of the subtle signs, such as silent chest, or may not understand medical language or parameters such as pH or PaCO<sub>2</sub>. A study could be conducted in the future from the patient perspective to add depth to the understanding of this event.

## **5.18 Conclusion**

A definition of near-fatal asthma, best achieved by consensus, is the first step to advance understanding of this type of attack and improve future management. The agreed definition was,

*“A near-fatal asthma attack occurs in a person who is exhausted, with severe dyspnoea, unable to speak with a silent chest. Respiratory arrest is considered imminent and invasive ventilation will likely be required. They will be responding poorly to emergency asthma therapies. A near-fatal asthma attack is associated with hypoxaemia with hypercarbia and a falling pH”*

It is difficult to predict whether the definition developed during this eDelphi process will be accepted within clinical practice, however it provides a working definition where one currently does not exist. We would hope that current asthma guideline committees, such as BTS/SIGN or the GINA strategy, will incorporate this definition and that mechanisms can be put into place to record the frequency of these episodes and monitor the associated outcomes of patients (BTS/SIGN, 2019, GINA, 2021). This eDelphi definition of near-fatal asthma attacks was shared with clinicians within the participant identification centres (PIC) to help select patients for the qualitative study on patient and parent perspectives on near-fatal asthma.

### **5.19 Summary and next steps**

In this chapter I have met the first aim of component one my PhD thesis – to identify a consensus definition of NFA. This definition was used for recruitment for the qualitative study on young adult and parent perspectives on near-fatal asthma which met the second aim of component one. In the next chapter I will present the methods used for component two of my research.

## **6 Chapter 6: Methods – Qualitative interview study**

### **6.1 Introduction**

This chapter outlines the methods utilised for the qualitative component of this thesis. I will discuss why a qualitative approach was necessary, and the process I used in my study design. I will explain how I used some of the fundamental components of grounded theory to conduct my research interviews, but ultimately decided to analyse my data using the structured approach offered by thematic analysis in order to identify themes and answer my research questions.

### **6.2 Arriving at a topic and study design**

I have been involved as a collaborator within the Asthma UK Centre for Applied Research (AUKCAR) since its launch in 2014. At the inaugural Annual Scientific Meeting (ASM), Leo Campbell, one of the Patient and Public Involvement (PPI) patient leads, spoke of his daughter's death due to an asthma attack. He wanted members of the audience to be aware that there were circumstances within his family that had contributed to her death. Following an initial discussion after this presentation between Steve Cunningham and Leo Campbell, a meeting was arranged in Edinburgh with Alison Worth (previous AUKCAR PPI lead), Steve Cunningham and I, to discuss an AUKCAR PhD study. This study was subsequently awarded funding from AUKCAR, with matched funding from the University of Edinburgh.

A qualitative study was designed as a single face to face interview with parents affected by NFA attacks and asthma related deaths. Young adults (16 years to 24 years of age) who had experienced a NFA attack were also included as participants. We initially discussed the inclusion of adolescents ( $\geq 10$  years of age) however after speaking with a couple of young people within the paediatric asthma clinic in Edinburgh, who said they could not recall the event, this age group was not included. I was aware of some of the challenges I would encounter with the study, which

included recruiting and interviewing a vulnerable group of participants. I understood that these challenges would be for both researcher and participants, but I had the opportunity to discuss these issues before applying for the studentship.

### **6.3 Reflexivity**

Reflexivity is the process of becoming self-aware (Begoray and Bannister, 2010). As a researcher it was important to consider my clinical experience, own bias and assumptions and how these could influence all stages of the research process. Finlay explains that the behaviour of the researcher will always affect participants' responses which will, in turn, influence the direction of findings. She further explains that qualitative research is regarded as a joint product of the relationship of a participant and researcher: It is co-constituted (Finlay, 2002). With reflexivity, researchers scrutinise and analyse the way their data are created (Finlay, 2017). I utilised supervision sessions to explore my professional influences further.

#### **6.3.1 Reflecting on my role in the research process**

I started my career as a nurse 30 years ago and have worked as a paediatric asthma nurse specialist for 19 years. During this time I have worked with families affected by NFA attacks and asthma deaths. I was also involved as a panel member of the National Review of Asthma Deaths (Levy et al., 2014). This involved reviewing the clinical case files of a person who had asthma recorded on their death certificate, and determining if the death was as a result of asthma. These experiences, alongside reading the enquiries presented in section 2.8, enhanced my knowledge and awareness of the factors that had been identified as possible causes contributing to both NFA attacks and asthma related deaths. On a personal level, I have family members who have asthma and have been able to appreciate that asthma is a condition which people live with, as opposed to a condition which defines them.

I was aware that I had some professional and evidence based assumptions about why NFA attacks and asthma deaths occurred, but the continued high rate of asthma death in the UK, suggested that these events were complex and multifactorial and had many unanswered questions and opportunities to learn. Designing this study allowed me to consider my personal and professional strengths, which include: my knowledge of asthma, my communication skills with children and families, particularly during stressful situations, and my ability to read non-verbal cues. Although my clinical role involves talking with parents, over the years I have learned the art of simply listening, which, is an important transferrable skill to this new role as researcher. However, it was also important for me to be mindful of my role while interviewing families, not imposing my views and assumptions, and allowing them to tell their stories in their own words.

I used my supervision sessions with Marilyn Kendal (MK), one of my qualitative research supervisors, to discuss my professional knowledge and how this may influence the different stages of the research process. We discussed the interviews and using more open questions. As participants were aware of my clinical background, some of them used terms such as, “but you know what I mean” or “you will understand that” but I asked them to explain what they meant rather than assume. For analysis and interpretation of findings we agreed I should keep a brief journal and write memos to help reflect on and address these assumptions (see section 6.16 for further discussion).

## **6.4 Qualitative research**

Qualitative research has come to the fore in health and social care research by providing ways of answering different sorts of questions, such as experiences of illness and quality of care, both in the form of independent research projects and complementing quantitative studies (Pope et al., 2002, Chapman et al., 2015) .

Qualitative methods are used to answer questions about experience, meaning and perspective, most often from the standpoint of those experiencing the phenomena under study (Hammarberg et al., 2016).

These data are usually not amenable to applying numerical values or statistics. Qualitative research techniques include a number of different ways to gather data which include:

- small-group discussions - for investigating beliefs, attitudes and concepts of normative behaviour
- semi-structured interviews - to seek views on a focused topic with key informants
- in-depth interviews - to understand a condition, experience, or event from a personal perspective
- analysis of texts and documents - such as reports, media articles, websites or social media postings, to learn about distributed or private knowledge.

Understanding what qualitative research means lead me to a recent paper by Aspers and Corte which aimed to define its meaning (Aspers and Corte, 2019). They defined qualitative research as,

*“an iterative process in which improved understanding to the scientific community is achieved by making new significant distinctions resulting from getting closer to the phenomenon studied”.*

They also identified four notions (a concept of or belief) as central to qualitative work: distinctions, process, closeness, and improved understanding (Table 44).



**TABLE 44: AN EXPLANATION OF THE FOUR NOTIONS WHICH HELP DEFINE QUALITATIVE RESEARCH ADAPTED FROM ASPERS AND CORTE (2019).**

| Notion                 | Explanation                                                                                                                                                                                                                                                       |
|------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Distinctions           | A key aspect of obtaining new knowledge                                                                                                                                                                                                                           |
| Process                | New knowledge results from a process that involves several phases, and above all iteration.                                                                                                                                                                       |
| Closeness              | Qualitative researchers get into direct <i>c</i> lose contact with those being investigated and/or the material being analysed                                                                                                                                    |
| Improved understanding | We obtain scientific knowledge of something that we as a scholarly community did not know before, or that we get to know something better. It means that we understand more about how parts are related to one another, and to other things we already understand |

By applying these notions to my work, I was able to question my current understanding of asthma deaths and NFA attacks, from previous studies and my clinical practice, and helped make new distinctions. Following a process of investigation and immersing myself in my data, this improved my understanding of the behaviours and circumstances that may contribute to these events, added to the current body of evidence, and led to further research.

Although I had always planned to conduct face to face interviews from study conception, once I started my studentship, I carried out some further reading into qualitative data collection as outlined above. I utilised my supervision sessions with MK to discuss these further. I considered the addition of a small face to face focus group or an online focus group using social media platforms (e.g. a closed Facebook page) however rejected these ideas for three reasons. Firstly, I felt the topic of discussion was too personal and sensitive to share in a face to face group setting. Although some parents may find a group supportive there was potential for causing distress in others by asking them to speak about a traumatic event such as death

(Sim and Waterfield, 2019). Secondly, I spoke with a bereaved parent who felt that she wanted her child's story to be heard independently of others, she felt this gave parents the opportunity to share their story in detail, without fear of judgement. Thirdly, with regard to online focus groups, I felt as a novice interviewer, I did not have the experience to conduct online research at this stage. Although there have been advances in information and communication technologies with the introduction of social media (e.g. Facebook and Twitter) and web conferencing platforms (e.g. Zoom, Microsoft Teams, Skype), research into the use of digital technologies as data collection tools is still at an early stage (Archibald et al., 2019). Using an online platform has its strengths which include: reaching participants over a large geographical area, cost effectiveness and convenience for both researcher and participants (Cater, 2011). There are limitations which include: variable internet speeds and quality of connection and the inability to read nonverbal cues and develop a rapport with a participant (Weller, 2017). My main concern was regarding support for the participants, especially if they needed to take a break from the interview, which, would be challenging online.

We also discussed using a narrative inquiry approach. Narrative inquiry is a type of qualitative research focused on human stories. It allows for a rich description of these experiences through storytelling, oral histories, photo voice projects, biography, autoethnography, or other human experience narrative methods (Ford, 2020). The narrative approach also provides an exploration of the meanings that the participants derive from their experiences and often amplifies voices that may have otherwise remained silent (Trahar, 2013). Through wider reading on the narrative inquiry method and discussion with MK I was aware of the relationship required between interviewer and participants. There was an expectation of active collaboration with the participant to ensure that their stories were understood and interpreted from their

point of view (Wang and Geale, 2015). This interaction was from the time of data collection and extended through to data analysis, interpretation of findings and discussion. Although the participants within this study would most likely have their own story to tell when it came to the question which related to the time their child had a near-fatal or fatal attack we agreed at this stage in my career as a qualitative researcher the narrative inquiry approach was not considered practical.

Therefore, for the purpose of this study, we felt the best approach was to undertake in-depth, semi structured interviews, face to face. We considered this approach as the most appropriate to meet the pragmatic aims and objectives of your health services research study.

Semi structured interviews typically consist of a dialogue between researcher and participant, led by a topic guide, and supplemented by follow-up questions and exploration of thoughts, feelings and beliefs and was appropriate for this deeply personal and sensitive topic (DeJonckheere and Vaughn, 2019). The topic guide was informed by lessons learned from confidential asthma enquiries (see section 2.8), newspaper articles and social media posts which included the Asthma UK (AUK) Facebook page. On the AUK page people openly shared their experiences of fatal and near fatal asthma attacks. Reading these social media posts helped reassure me that parents were willing to discuss these events publicly.

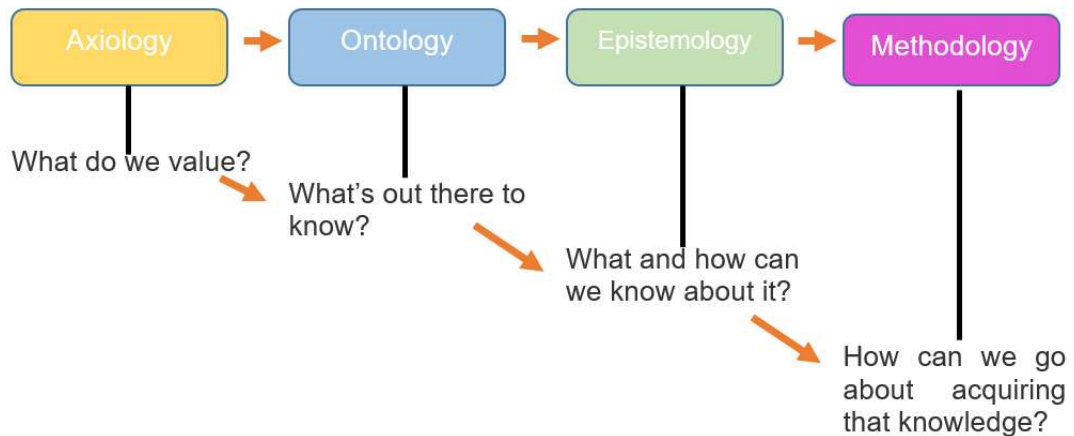
## **6.5 The research paradigm**

A research paradigm, or set of common beliefs about research, should be a key feature of the design of any research study (Brown and Dueñas, 2020). It is important to detail the research paradigm as this will guide how problems are solved and directly influence methods choice (Schwandt, 2014). Brown and Dueñas explain that the paradigm of a study is constructed of several “building blocks,” detailed in Figure 28.

This is an adapted version from Grix's paradigmatic building blocks (Grix, 2002) which includes axiology added by Brown and Dueñas.

**FIGURE 28: THE BUILDING BLOCKS FORMING THE RESEARCH PARADIGM AND HOW THEY INTERRELATE.**

Adapted from Brown and Dueñas (2020) and Grix (2020)



### 6.5.1 Axiology, ontology and epistemology

Axiology considers what would be of value to research and how to conduct research ethically (Patteron and Williams, 1998). Brown and Dueñas suggest using a reflective approach and consider three questions:

- Why is this research worth my time and attention?
- What motivates me?
- Do I believe this research is valuable and will inform practice?

Experience of caring for families following NFA attacks/ asthma deaths and witnessing the distress and grief which occurs, provided me with motivation to expand my current beliefs. Understanding NFA attacks and asthma deaths from the parents perspective, is fundamentally important to improve the understanding of the lived experience and to try and identify ways to educate families that may in the future, prevent NFA attacks, and reduce asthma deaths.

Research philosophy comprises conscious and unconscious considerations and assumptions, regarding the nature of reality (ontology) and the creation of knowledge and understanding (epistemology) (Biedenbach and Jacobsson, 2019). To assess my ontological and epistemological assumptions it was important to consider the stance of the four most common paradigms in medical research: positivism, post-positivism, constructivism/ interpretivist and critical theory which are presented in Table 45 (Brown and Dueñas, 2020). From this comparison table, I feel my assumptions lie within a constructivism/ interpretivist paradigm. I believe personal experiences are individual to that person however there will be similarities from other individuals when discussing a similar event. Narratives from the same individual could change depending on factors such as, time from the event, or emotional state, so I was keen to use one version of the experience and decided not to use member checking within this study (see section 9.7.4).

**TABLE 45: ONTOLOGICAL AND EPISTEMOLOGICAL ASSUMPTIONS OF POSITIVISM, POST-POSITIVISM, CONSTRUCTIVISM/INTERPRETIVISM AND CRITICAL THEORY.**

Adapted from Brown and Dueñas (2020)

| Paradigm                    | Positivism                                                                                 | Post-positivism                                                                                                                       | Constructivism/<br>interpretivist                                                                          | Critical theory                                                                                                                                                          |
|-----------------------------|--------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Ontological assumptions     | There is a single, objective reality that can be observed through science.                 | There is a single, objective reality. However, scientific observations involve error so reality can only be known imperfectly.        | There are multiple subjective realities, each of which is socially constructed by and between individuals. | There are multiple subjective realities influenced by power relations in society. Reality is shaped by social, political, cultural, economic, ethnic, and gender values. |
| Epistemological assumptions | Neutral knowledge can be obtained through the use of reliable and valid measurement tools. | Obtaining knowledge is subject to human error. Therefore, human knowledge is imperfect and only “probable” truths can be established. | Knowledge is subjective and formed at an individual level.                                                 | Knowledge is also subjective, but created and negotiated between individuals and within groups.                                                                          |

## 6.6 Methodology

Selecting an appropriate theoretical framework for my research was an important and necessary process. Grant and Osanloo suggest that the selection of the framework requires a deep and thoughtful understanding of your problem, purpose, significance, and research questions (Osanloo and Grant, 2016).

**Problem** – I was aware that despite numerous confidential enquiries identify contributing factors (see section 2.1), the number of asthma deaths have been steadily increasing in the UK. Near fatal asthma is a recognised type of asthma attack, however it was without definition, and was not recognised within medical coding. As a result, the true incidence of NFA attacks remains unknown. The experiences of those affected by NFA and asthma death, to my knowledge, have not been explored, leaving a gap in understanding, which required further investigation.

**Purpose** – the purpose of this research was to identify experiences during an asthma attack or behaviours/ circumstances which may increase risks of both an attack and asthma death. Such knowledge could inform practice for key stakeholders which includes: children and young people (CYP) with asthma and their families, education, primary care, severe asthma registries and emergency service responses.

**Significance** – the significance of this research lies within the platform of work identified by the AUKCAR in preventing NFA attacks and reducing the number of asthma deaths in children and young people (see section 1.2).

**Research questions** – were aligned with the study aims (see section 2.9).

Barbour argues that in practice, many researchers borrow from more than one approach, often with good effect, which leads to a hybrid approach (Barbour, 2014). With these constructs in mind, I believed using aspects of grounded theory would be an appropriate theoretical framework to use, with a different approach to analysis i.e. thematic analysis.

### **6.6.1 Grounded theory**

Grounded theory (GT) consists of systematic, yet flexible methods for collecting and analysing data to construct theories from the data themselves (Charmaz, 2014). Its methods offer a general set of principles, strategies and guidelines, which enables the researcher to discover or learn something for themselves, rather than being prescriptive. The data allows the researcher to develop theoretical analysis from the outset of the study. In this study, it provided me with the opportunity to learn from the participants about their experience of living with asthma and the impact of the events I wished to explore. Early analysis of data, through coding (see section 6.15), was imperative to try and identify commonalities and contrasts, which provided ideas to include in the topic guide for future interviews.

#### **6.6.1.1 The historical context of grounded theory**

Glaser and Strauss introduced the concept of grounded theory with their publication 'The Discovery of Grounded Theory' (Glaser and Strauss, 1967). Sbaraini describes how over time grounded theory has evolved into four main types: Barney Glaser's '*Classic Grounded Theory*', Anselm Strauss and Juliet Corbin's '*Basics of Qualitative Research*', Kathy Charmaz's '*Constructivist Grounded Theory*' and Adele Clarke's postmodern '*Situational Analysis*' (Sbaraini et al., 2011).

There are fundamental components included by all GT theorists (Table 46) to consider when using grounded theory methods. Through discussion with MK and DC, I chose not to utilise all of the methods within my study namely analysis and coding, with a preference for thematic analysis (section 6.14). I also chose purposive sampling rather than theoretical sampling as I had a strict criteria for recruitment.



**TABLE 46: THE FUNDAMENTAL COMPONENTS OF A GROUNDED THEORY STUDY**

Adapted from Sbarini et al. 2011

| Component             | Stage                        | Description                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|-----------------------|------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Openness              | Throughout the study         | Grounded theory methodology emphasises inductive analysis. Induction moves from the particular to the general: it develops new theories or hypotheses from many observations.                                                                                                                                                                                                                                                                    |
| Analysing immediately | Analysis and data collection | In a grounded theory study, analysis must commence as soon as possible, and continue in parallel with data collection                                                                                                                                                                                                                                                                                                                            |
| Coding and comparing  | Analysis                     | Data analysis relies on <i>coding and</i> comparing data with data, case with case, event with event, code with code, to understand and explain variation in the data                                                                                                                                                                                                                                                                            |
| Memo writing          | Analysis                     | Memos are used to stimulate and record the analysts' developing thinking, including the <i>comparisons</i> made                                                                                                                                                                                                                                                                                                                                  |
| Theoretical sampling  | Sampling and data collection | Theoretical sampling is designed to serve the developing <i>theory</i> . Analysis raises questions, suggests relationships, highlights gaps in the existing data set and reveals what the researchers do not yet know. By carefully selecting <i>participants</i> and by modifying the <i>questions</i> asked in data collection, the researchers fill gaps, clarify uncertainties, test their interpretations, and build their emerging theory. |

| Component                          | Stage                                  | Description                                                                                                                                                                                                                                                                     |
|------------------------------------|----------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Theoretical saturation             | Sampling, data collection and analysis | In a grounded theory study, theoretical saturation is sought. This is a subtly different form of saturation, in which all of the concepts in the substantive theory being developed are well understood and can be substantiated from the data.                                 |
| Production of a substantive theory | Analysis and interpretation            | The results of a grounded theory study are expressed as a substantive theory, that is, as a set of concepts that are related to one another in a cohesive whole. As in most science, this theory is considered to be fallible, dependent on context and never completely final. |

## 6.7 Study population

This study investigated parent/ carer perspective in those whose child was aged between five years and 24 years of age at the time of the NFA attack or asthma death. It also included young adults aged between 16 years and 24 years who experienced NFA. The rationale for including these age groups was twofold. Firstly, diagnosing and defining asthma in early childhood (<5 years old) has been a matter of controversy (Moral et al., 2019). This is mainly because of the inability to perform objective lung function testing, and the high frequency in resolution of symptoms in the pre-school years (Elenius et al., 2021). Children aged five years and above can generally perform spirometry, which, in conjunction with a detailed clinical history, will confirm either a suspicion of asthma, or an asthma diagnosis (BTS/SIGN, 2019). Selecting children aged five years and above for this study excluded other medical wheezing conditions, which could also result in near fatal events or death, such as

bronchiolitis and viral wheeze. Secondly, I considered the development of the adolescent brain and their approach and response to risk taking. The adolescent period has been extended to include the period from 10 years to 24 years of age (formerly 19 years) as this time period corresponds more closely to adolescent growth and brain development (Sawyer et al., 2018). Risk taking is a complex process and a key question is whether adolescents are developmentally competent to make decisions (Reyna and Farley, 2006). Reyna and Farley explain that when an adolescent is in full possession of the facts regarding a risky situation they are more risk-averse than an adult and I was keen to see if this was evident in the study population. Adolescent decision-making typically occurs in busy environments that often involve complex motivations such as peer status, achieving goals and finding independence, and they may be less likely to prioritise health needs (Roberts et al., 2020).

## **6.8 Inclusion and exclusion criteria**

The criteria used for inclusion and exclusion for the three parts of the qualitative study are listed below.

### **6.8.1 Near-fatal interviews - inclusion criteria**

- Parent(s) or carer(s) who was present at the time their child, adolescent or young adult aged between 5 years and 24 years old (at the time of the attack) experienced a near fatal asthma attack.

or

- Young adult (16 – 24 years) who has experienced a near fatal attack.

And

- Fluent in English
- Event occurred within the last 10 years (parent/carer) 5 years (Young Adult)
- All genders and ethnicities.

- Living in mainland Scotland, England, Wales and NI
- Able to give informed consent.

#### **6.8.2 Fatal attack interviews - inclusion criteria**

- Parent(s) or carer(s) of a child, adolescent or young adult aged between 5 years and 24 years old (at the time of the attack) whose child has died of an asthma attack.
- Present at the time of the event.
- Fluent in English.
- Event occurred within the last 10 years.
- All genders and ethnicities.
- Living in mainland Scotland, England, Wales and NI.
- Able to give informed consent.

#### **6.8.3 Near-fatal interviews – exclusion criteria**

- Event occurred outwith the ages of 5 years and 24 years.
- Parent(s)/ carer(s) not present at the time of the event.
- Not fluent in English.
- Event occurred more than 10 years ago (Parent / Carer) or 5 years (young adult).
- Living in Scottish Islands/ Isle of Man/ Isle of Wight.
- Unable to give informed consent.

#### **6.8.4 Fatal attack interviews – exclusion criteria**

- Event occurred out with the ages of 5 years and 24 years.
- Not fluent in English.
- Event occurred more than 10 years ago.
- Living in Scottish Islands/ Isle of Man/ Isle of Wight.

- Unable to give informed consent.

## **6.9 Sampling**

Sampling is one of the most important aspects of research design (Guest et al., 2013). It refers to the process of selecting a subset of people from a defined population for inclusion into a study. I used two methods of sampling; purposive and snowballing. Purposive sampling refers to choosing a participant based on the purpose of their involvement in the study (Sharma, 2017). I was keen to have a variety/ diversity of views and placed minimal exclusion criteria to recruitment. As this was a rare and hard to reach group sampling, I had to supplement purposive sampling with snowballing. Snowballing involves existing study participants recruiting future participants from their acquaintances (Sharma, 2017). Potential participants for the near fatal studies (parent and young adults) were identified by their clinical teams using criteria (criterion sampling) provided and sent a letter of invitation. I was unaware of the number of patients invited by each centre however the participants who came forward were varied in age, geographical location and socioeconomic status. Parents who participated in the fatal asthma study again matched criterion for inclusion. This was a difficult group to engage with, as I used the social media of charitable websites to advertise the study. The study was also advertised within the AUK research volunteer newsletter. Some of the participants who had taken part, and a PPI volunteer, shared details of the study with other parents (snowballing) within their closed Facebook pages which helped to recruit three participants. All participants who took part in the fatal asthma study contacted me directly via email.

## **6.10 Recruitment**

Participants were recruited to this study using two different methods, one for the near fatal patients and families and one for families affected by asthma deaths, as described in detail below. Both methods relied on the participants making initial

contact with me. After reading the PIS they could either request further information before making a decision about participation or arrange an interview. They had the option to do both of these by phone, email or text however I spoke with all participants before the interview to ensure they met criteria for inclusion in the study and did not have any unanswered questions.

#### **6.10.1 Near-fatal asthma study**

Patients who had experienced a NFA attack are recommended to have clinical follow up indefinitely from an experienced respiratory team (BTS/SIGN, 2019). We therefore engaged with clinicians in 13 hospitals within Scotland and England, who agreed to act as Participant Identification Centres (PIC) and distribute letters of invitation to take part in the study (appendix 4 & 5). The clinical teams did not share any details of the process used to identify potential participants but provided numbers for both young people and parents, to which invitations were sent. I am unaware if potential participants were therefore excluded from participation if English was not their first language. An email was sent to the clinical teams, which included the inclusion and exclusion criteria for the study. They were also provided with the consensus definition of near-fatal asthma (see section 5.18) which was agreed in the eDelphi study to inform recruitment however they also had the option to invite patients who they believed had experienced a NFA attack, which fell outwith the definition. Forty five invitations from 13 centres were sent to potential participants, six to young adults and 39 to parents (Table 47).

**TABLE 47: NUMBER OF INVITATIONS SENT TO POTENTIAL PARTICIPANTS FROM PIC.**

| PIC                                                    | Number of invitations sent to potential participants | Additional comments from PIC                                                                       |
|--------------------------------------------------------|------------------------------------------------------|----------------------------------------------------------------------------------------------------|
| Royal Hospital for Sick Children, Edinburgh            | 8                                                    | 2 young adults, 6 parents                                                                          |
| Royal Infirmary of Edinburgh                           | 0                                                    | No potential participants were identified within the 16-24 age range                               |
| Royal Hospital for Children, Glasgow                   | 2                                                    | Preferred to discuss with parents at clinic and then send information                              |
| Royal Aberdeen Children's Hospital                     | 0                                                    | No potential participants were identified                                                          |
| Ninewells Hospital, Dundee                             | 5                                                    | 2 young adult, 3 parents                                                                           |
| Birmingham Women's and Children's NHS Foundation Trust | 6                                                    | Discussed at clinic and then sent information by post<br>1 young adult                             |
| Royal Brompton & Harefield NHS Foundation Trust        | 2                                                    | Preferred to discuss with parents at clinic/ planned inpatient admission and then send information |
| King's College Hospital NHS Foundation Trust           | 0                                                    | No response from PIC site                                                                          |
| Alder Hey Children's NHS Foundation Trust              | 0                                                    | Potential participants are moved onto adult services and no approval to use adult hospital as PIC  |
| Manchester University NHS Foundation Trust             | 0                                                    | No response from PIC site                                                                          |
| The Newcastle Upon Tyne Hospital NHS Foundation Trust  | 22                                                   | 2 young adult, 20 parents                                                                          |
| Sheffield Children's NHS Foundation Trust              | 0                                                    | Delay in approval to help recruit participants from their local R&D                                |
| University Hospitals of North Midlands NHS Trust       | 0                                                    | No response from PIC site                                                                          |
| Total of invitations sent                              | 45                                                   |                                                                                                    |

### 6.10.2 Fatal asthma study

Participants for this aspect of the study were not necessarily known to or in contact with clinical teams. Prior to the Research Ethics Committee (REC) application, I contacted Asthma UK (leading asthma charity in the UK) and Child Bereavement UK (bereavement charity for parents or children affected by death) to ascertain their

willingness to advertise the study on their social media pages. Both charities agreed in principle and a study advert was produced in collaboration with PPI volunteers from AUKCAR. They agreed to advertise the study on their websites, social media pages and send an email to their lay volunteers. Allergy UK (leading allergy charity in the UK) was later added as an advertising source. Potential participants had the option to contact the research team by email, phone or text. All potential participants were contacted to ask for consent to send a copy of the PIS, which was sent with an accompanying email (Appendix 6).

### **6.11 Consent**

The informed consent process provided essential study information to potential participants and allowed them to make an informed decision about participation in a research study (Kadam, 2017). Following initial contact from a potential participant, I confirmed eligibility and requested consent to send the PIS via email, or post, if this had not already been accessed online, or sent via clinical teams. I ensured potential participants had a minimum of 24 hours after receipt of the information to arrange a follow up phone call, to schedule an interview date and time, if they agreed to take part. This also gave the potential participant the opportunity to ask any questions they may have had at that stage. After reading the PIS, potential participants could change their mind at any time and were given the options of emailing or texting 'stop'. They did not need to provide an explanation. If I was unable to speak with a potential participant who had responded to either an initial PIC invitation and/or social media advertisement, a follow up email was sent. If I did not receive a reply, no further emails were sent, and it was assumed they did not wish to participate.

Informed consent was taken in person prior to commencing the interview. The participant was given time to ask further questions before signing consent. We discussed active withdrawal of consent at any time during the interview, or if they



became unduly distressed. Participants consent was for the duration of the study and for the future use of their anonymised transcripts in ethically approved studies (Appendices 7, 8 &9).

### **6.12 Interviews**

The interviews were a single face to face meeting lasting, between 35 minutes and an hour, depending on the participant. They were mostly conducted in the participant's home for bereaved parents, with the exception of one who preferred to meet in a community setting. Carrying out the interviews within a safe and familiar environment led to the participant feeling more at ease. A similar approach had been used in other studies which explored parents' experience of bereavement (Butler et al., 2018a, Butler et al., 2018b). The interviews for those affected by NFA attacks (parent or young adult) were conducted in either the family home, hospital or community setting, dependent on participant's choice.

Semi-structured interview topic guides (appendix 10 &11) were devised using examples from Charmaz's sample of interview questions about life changes which included initial open-ended questions, intermediate questions and ending questions (Charmaz, 2014). The topic guide was discussed with PPI volunteers, to ensure appropriate questions were being asked in a sensitive manner. Taking into consideration the aims of the study (see section 2.9), two aspects were explored: Firstly, leading up to the event, it was important to uncover the background to these attacks. Awareness of the length of time the participants or families had lived with asthma, possible triggering factors, knowledge of asthma and how previous attacks had been managed were all important factors to consider, to provide context. This would help identify behaviours or circumstances that could be potentially modified in the future. Secondly, exploring the event, would hopefully reveal some key time critical factors, which could be incorporated in education programmes for families and

healthcare professionals or be used in algorithms for emergency services. These guides were reviewed after every two - three interviews to take into account commonalities and contrasts and amendments were made to the guide.

### **6.13 Transcribing**

The interviews were all recorded using an Olympus DS-3500 with data encryption for an added level of security and confidentiality. This digital voice recorder was recommended by the University of Edinburgh Information Support team and used by other researchers within the Usher Institute. Transcribing is a time consuming process with a suggestion by Bailey that it will take at least three hours per hour of talk and up to 10 hours per hour of talk with a fine level of detail including visual detail (Bailey, 2008). Transcription plays a critical part of the first stage of the analysis of qualitative data therefore it was important to fully immerse myself in the data which offered new insight on each occasion (Stuckey, 2014).

The study budget for this research included funding for a transcription service. Therefore, 1<sup>st</sup> Class secretarial services (a Lothian based transcription service) was utilised. A copy of their Client Charter which detailed their data protection and client confidentiality policies and procedures was provided, along with assurance that their systems were recently assessed and approved by the University. The server used by 1<sup>st</sup> class secretarial is a CentOS Linux Server which runs a MySQL database. The server is located within the EU in a dedicated data storage facility in Germany, which has no public access. From a transactional viewpoint, all transactions run over the transcription server (<https://transcription.1stclass.uk.com>) over https using an enhanced validation 2048 bit/ 256bit SSL certificate.

Recorded interviews were initially downloaded to a password protected university laptop. Following encryption, the files were uploaded to the transcription services website, with a note of the password for the files provided separately. With each

uploaded interview file, a note was included outlining the sensitive and potentially distressing nature of the interview, to prevent undue distress to the audio typist. All files were transcribed using 'intelligent verbatim' transcribing with a 10 day turn around service. On receipt of the transcribed files, I used the process as outlined in Table 48 to anonymise the participants, check the accuracy of the transcriptions and add in some additional field notes and observations. All recordings were deleted after I had listened to, alongside reading, the transcripts three times.

**TABLE 48: AN EXPLANATION OF THE TRANSCRIPTION PROCESS USED IN THIS STUDY.**

| Anonymising participants data           | After transcription                                                                                                       | Transmission of meaning to text                          |
|-----------------------------------------|---------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| Participant given a study number.       | Playback interview and check to ensure transcription is accurate and any inaudible or voice over laps amended if possible | Use of italics/ bold text for inflection                 |
| Interview recorded via encrypted device | Removal of names, places or other identifiable data                                                                       | Capture meaning through use of pauses/ breaks or emotion |

#### 6.14 Analytic process

Barbour advises that the key to effective qualitative research is to have a methodical approach and to consider the challenges analysing data will bring (Barbour, 2014). Rapley further acknowledges the quandary a novice qualitative researcher will face in deciding which approach should be used to make sense of the data and suggests comparing a number of different approaches, and making a decision based on further reading (Rapley, 2016). I preferred the approaches of constructivist grounded theory (Charmaz, 2014) and thematic analysis (Braun and Clarke, 2006) and found the comparison table (Table 49), which also compared framework analysis and interpretative phenomenological analysis, (by Rapley) an ideal starting point.

**TABLE 49: A COMPARISON OF KEY PROCESSES FROM DIFFERENT ANALYTIC APPROACHES ADAPTED FROM RAPLEY (2016).**

| Thematic Analysis<br>(Braun and Clarke 2006) | Constructivist grounded theory<br>(Charmaz 2014)                           |
|----------------------------------------------|----------------------------------------------------------------------------|
| Familiarise yourself with the dataset        | Initial coding and memo writing (line by line coding, constant comparison) |
| Generate initial codes                       | Focused coding and memo writing                                            |
| Search for themes                            | Collect new data via theoretical sampling                                  |
| Review themes                                | Continue to code, memo and use theoretical sampling                        |
| Refine themes                                | Sort and integrate memos.                                                  |

As a clinician, I found some of the terminology used within constructivist grounded theory challenging and lacking a clear structure. Through discussion with MK, reading examples of other qualitative studies around bereavement and trauma and comparing both of these approaches, I felt thematic analysis was the most appropriate method for analysing my data. Braun and Clarke believe it is the first method of analysis that researchers should learn, as it provides core transferable skills to other forms of analysis which resonated with me (Braun and Clarke, 2006).

### **6.15 Coding and identification of themes**

Thematic analysis is based on six phases with phases one - five focusing on coding and developing themes, and the final phase six, is producing a report. The familiarisation phase of analysis gave me the opportunity to consider initial ideas, which I wrote as memos (phase one). As I read through the transcripts, I made notes of initial codes – some applied to single sentences, whilst other applied to paragraphs. I found it easier to do this directly onto the transcripts, and made notes of codes in a notebook. As I was exploring data from a previously unexplored perspective, I used a ‘data driven’ approach to coding rather than ‘theory driven’. I also followed the key advice recommended by Braun and Clarke in this phase (phase two): code for as many themes/ patterns as possible, code extracts of data inclusively and code individual extracts of data into as many different themes as they fit into (Braun and

Clarke, 2006) . Debbie Cavers (DC) had become my new qualitative research supervisor following the retirement of MK. DC also coded the transcripts which was helpful for two reasons; firstly to add rigor to the coding process, but also as a personally supportive measure in this process. Our ideas were very similar, and I was able to consider the helpful suggestions provided. This enabled me to start searching for themes (phase three). Having collated a long list of codes, I re-focused my attention to identify broader themes, grouping different codes under these headings with the assistance of Nvivo as my data manager (see section 6.17). I was able to identify a collection of candidate themes, alongside subthemes, before moving on to reviewing themes (phase four). This phase involved two levels of reviewing and refining themes. As a team, we discussed the themes to ensure they were forming a coherent pattern reflective of the data. Importantly, at this stage, I revisited the transcripts to ensure that I had not missed any data which would subsequently fit within the themes, before moving forward to the penultimate phase (phase five) defining and naming themes and producing my findings chapter.

### **6.16 Memo writing**

Memo writing is most commonly associated with grounded theory, however it can be utilised within all forms of qualitative research (Birks et al., 2008). Using the mnemonic 'MEMO': Mapping research activities; Extracting meaning from the data; Maintaining momentum; Opening communication helped with understanding the function of memoing throughout the study, and enabled me to engage with the data at a depth which otherwise would have been difficult to achieve. Memos were written in the study design phase, immediately after the interviews had taken place and also during the coding process. They also assisted in further discussion with members of the research team in the exploration of commonalities and differences in the data.

## **6.17 NVivo**

In order to assist in the management of data I used NVivo pro version 11. This gave me the opportunity to organise, store and retrieve my data more efficiently, which ultimately assisted in time management. It also provided a function to produce mind maps to help display the study findings visually (see sections 7.4 & 8.3).

## **6.18 Ethical considerations**

It was important for me to consider the moral and ethical dimensions of this research. I considered the broad ethical issues related to interviewing this vulnerable group and how this would shape the study design. This included the timing of the interviews in relation to how soon after a fatal or near fatal attack it would be appropriate to invite participants to this study. I also considered the questions to include in the topic guide as they needed to be asked in a sensitive manner. I considered these issues relating to both fatal and near fatal asthma attack interviews.

### **6.18.1 Fatal asthma**

There is tension around the concept of research with bereaved parents, with debate about the ethics of approaching bereaved parents when they are grieving, and the most appropriate time to invite them to take part in research (Hynson et al., 2006). As I prepared my Integrated Research Application System (IRAS) submission for the NHS ethics committee, it was vital I provided as much supportive information as possible. My IRAS application included information which was evidence based but it also contained support from PPI volunteers within AUKCAR, including a letter of support to the committee from Leo Campbell (Appendix 12).

A study from Bentley and O'Connor explored 'when is the right time to ask' research questions, and found that 86% of the 22 bereaved families they interviewed believed a minimum period of five months to be appropriate, with 43% feeling ready within a number of weeks (Bentley and O'Connor, 2015). Some of their participants felt that

recall would diminish over time, or they would be less likely to want to recall certain aspects of the event. Butler et al however waited for a minimum of 6 months before approaching families, to avoid early intense grief and to minimise the impacts of memory and recall bias on data collection (Butler et al., 2018). In their study, many parents also noted that talking about their experiences would always hurt, but felt that at 12 months, enough time had passed that the interview was not significantly painful for them. The key messages from these studies, and the evidence they cite within them, are that people grieve differently, they want to be asked, and they can (and will) say no, to either research participation, or a line of questioning.

A key issue in this part of my study was the timing of when to approach potential participants to ensure it did not cause undue distress. Through discussion with members of the research team and PPI volunteers, we agreed that timescales of a minimum of six months, and a maximum of ten years, would be applied to this study. One of the main reasons for this long time frame, was the numbers of children who die each year being relatively low and the expected difficulties to recruitment this would pose.

#### **6.18.2 Near-fatal asthma**

Interviewing parents and young adults following a near death experience raised another ethical dilemma. Past research and clinical experience suggest that young people with asthma and their parents may be at risk of post-traumatic stress (PTS) following an asthma-related event, particularly events that are life threatening (Kean et al., 2006). Kean et al further explains that specifically within paediatric asthma, experiences of not being able to breathe, undergoing stressful medical procedures and believing that you (or your child) may die, have been viewed as traumatic. It is difficult to predict if all young adults and their parents would experience these feelings, but important to be aware this may be an issue. There was a general lack of guidance available as to when it would be appropriate to interview parents and young adults

after a life threatening event. Again with guidance from the PPI volunteers, we agreed within a maximum of 10 years, with no minimum timeframe. The REC panel however felt that 10 years was too long for a young adult and asked for this to be amended to a maximum of 5 years.

#### **6.18.3 Interviewer safety and distress**

The research participants were located in England and Scotland and I travelled and conducted the interviews alone. This issue was raised by the REC committee, as they were concerned about my personal safety. In my specialist nurse role I regularly visit families at home and have received training on lone working and management of violence and aggression. The University of Edinburgh has a lone worker policy therefore all interviews were conducted within University working hours and risk assessed (to the best of my knowledge). Taking into account protecting the identity and confidentiality of the participant versus personal safety, I had a procedure of emailing my supervisors (SC and MK) with the address of the participant and proposed interview time. After the interview, I emailed them again to advise the interview was complete. After each interview I had the opportunity to debrief with my supervisors. I conducted no more than two interviews in a week, and found benefit in using a reflective diary which was helpful to identify any patterns in my thought process or recurrent concerns. We had discussed the option of external counselling if I felt overwhelmed with the emotional impact of interviewing, however I did not feel this was necessary.

#### **6.18.4 Participant safety and distress**

I anticipated parents/ carers or young people may become upset during the interview. Before the interview commenced, I discussed this with participants and advised them to take as many breaks as they needed. I also utilised nonverbal cues to pace the conversation and to introduce breaks. I used the sentence, "Do you feel ready to talk about the event when... (NFA/death)", and was able to take direction from the



participant. Plans were in place after the interview terminated, to ensure that no participant was left unduly distressed. If there were any concerns about the safety of the participant at the end of the interview, I had a predetermined plan to contact a family member. The participants GP and, if applicable, clinical teams were informed of participation in this study. The day after the interview, if appropriate, I planned to contact the participant to ensure the distress has resolved and answer any questions the participant may have. A follow up letter of thanks was sent, along with details of available resources to help with grief (Cruse and Child Bereavement UK) and asthma (Asthma UK Nurses Helpline) if requested.

#### **6.18.5 Transcriber distress**

1<sup>st</sup> class Secretarial Services, Scotland was used as the external transcription service. They have measures in place to protect the transcriber. All employees are provided with details of the nature of the interview, and can self-select if they want to take the assignment.

#### **6.18.6 Disclosure**

There was potential that a participant would make a disclosure during an interview which I felt should be referred to another professional or service. This risk was identified by the REC panel and they requested an addition to the PIS for the fatal asthma study.

The disclosure may have related to either a child or adult.

**Safeguarding a child** – Any concerns would be discussed with SC or LF (both senior clinicians) in the first instance, and if deemed necessary, would have been escalated to social services in the locality of the participant.

**Safeguarding an adult** – Any concerns would be discussed with SC or LF in the first instance, and if deemed necessary, will be escalated to the GP for the participant.

Interestingly, my only concern during this study, related to a participants' child in the near fatal asthma study. The child was experiencing daily asthma symptoms which

affected her quality of life. I was concerned she was at risk of another attack therefore this was discussed with SC. We agreed that I would ask permission from the participant to pass on concerns to the clinical team. The parent agreed to this and I contacted the child's asthma specialist nurse to pass on this information.

### **6.19 Ethical approval**

Ethical approval for this study was granted by the West of Scotland Research Ethics Committee 3 on 22<sup>nd</sup> May 2018 (REC ref 18/WS/0072). A summary of the study was published on the Health Research Authority website (IRAS project ID: 237440) (Appendix 13).

### **6.20 Summary and next steps**

This chapter has presented the methods used in the qualitative component of this thesis. The following chapter will present the findings of the qualitative interviews.

## **7 Chapter Seven: Findings from the interviews with parents and young adults on their experience of a near-fatal asthma attack.**

### **7.1 Introduction**

The previous chapter outlined the methods I utilised for the qualitative phase of my PhD. Using aspects of a grounded theory approach and thematic analysis, the experiences of parents and young adults affected by a NFA attack were explored, to address the aims of component two of my study (see section 2.9). This chapter reports the findings of the 15 semi-structured interviews (five young adults and ten parents), and includes details of participant characteristics. Quotations are provided in support of the constructed themes and sub themes.

### **7.2 Young adult participants**

Seven invitations were sent to young adults (16 to 24 years of age) to participate in the study via four Participant Identification Centres (PIC). The majority of the PIC's (n=12/13) were paediatric facilities and no longer had a clinical responsibility for young people in the recruitment age group. The invitation attracted five young people to participate in semi-structured interviews lasting between 32 and 43 minutes. They had all experienced NFA attacks within the last five years. The characteristics of the young people are displayed in Table 50. The interviews took place in either the young person's home (n= 4/5) or at their local hospital (n=1/5). The young adult who chose to have his interview at the local hospital was attending a clinic review and, as he was in full-time employment, this was the most suitable option for him.

**TABLE 50: CHARACTERISTICS OF THE YOUNG ADULTS WHO PARTICIPATED IN THE NFA ATTACK INTERVIEWS IN ORDER OF INTERVIEW DATE.**

| Participant number                               | NFAYA01        | NFAYA02        | NFAYA 03      | NFAYA 04      | NFAYA 05       |
|--------------------------------------------------|----------------|----------------|---------------|---------------|----------------|
| Gender                                           | M              | M              | M             | F             | F              |
| Age                                              | 24             | 23             | 21            | 16            | 21             |
| Ethnicity                                        | White Scottish | White Scottish | White English | White English | White Scottish |
| Geographical location                            | Scotland       | Scotland       | North England | Midlands      | Scotland       |
| Years since NFA                                  | 5years         | 2years         | 5years        | 6 months      | 5 years        |
| BTS/SIGN Step at time of attack                  | 4              | 5              | 4             | 4             | 3              |
| Onset of attack (Sudden <sup>7</sup> or gradual) | Sudden         | Gradual        | Gradual       | Gradual       | Sudden         |

\*NFAYA = near fatal asthma young adult

### 7.3 Parent participants

Twelve parents of children who had experienced a NFA attack within the last ten years participated in ten semi structured interviews lasting between 32 and 68 minutes. Two of the interviews were conducted as joint parent interviews, at the request of the parents on the day of the interview. The characteristics of the parent(s) and their child are displayed in Table 51. The interviews took place in either the participant's home (n= 6/10), a local community venue (n=2/10), or at their local hospital (n=2/10). For those who chose to have the interview in a local venue, one of the participants chose to have the interview conducted at her place of employment and the other chose a local youth zone. The participants who chose to have the interviews conducted at the local hospital were attending appointments.

<sup>7</sup> Sudden onset is defined as within a two hour time period

**TABLE 51: CHARACTERISTICS OF THE PARENT(S) AND THEIR CHILD WHO PARTICIPATED IN THE NEAR FATAL ASTHMA INTERVIEWS IN ORDER OF INTERVIEW DATE.**

| Participant number                               | NFA01          | NFA02          | NFA03          | NFA04          | NFA 05        | NFA06 & NFA07 | NFA08         | NFA09 & NFA10  | NFA11         | NFA12         |
|--------------------------------------------------|----------------|----------------|----------------|----------------|---------------|---------------|---------------|----------------|---------------|---------------|
| Gender(s) of participant                         | F              | F              | F              | F              | F             | M & F         | F             | M & F          | F             | F             |
| Gender of child                                  | M              | F              | F              | F              | F             | M             | F             | M              | F             | F             |
| Age of child at time of NFA                      | 17 years       | 13 years       | 13 years       | 8 years        | 14 years      | 8 years       | 8 years       | 20             | 15 years      | 16 years      |
| Ethnicity                                        | White Scottish | White Scottish | White Scottish | White Scottish | White English | White English | White English | White Scottish | White English | White English |
| Geographical location                            | Scotland       | Scotland       | Scotland       | Scotland       | North England | North England | North England | Scotland       | North England | North England |
| Time since NFA                                   | 9 years        | 6 months       | 7 years        | 4 years        | 2 years       | 6 months      | 10 months     | 2 years        | 6 months      | 1 year        |
| BTS/SIGN <sup>8</sup> Step at time of the attack | 4              | 2              | 3              | 1              | 5             | 2             | 3             | 5              | 4             | 4             |
| Onset of attack (Sudden or gradual)              | Sudden         | Gradual        | Sudden         | Gradual        | Gradual       | Gradual       | Sudden        | Gradual        | Gradual       | Gradual       |

\*NFA = near fatal asthma

<sup>8</sup> BTS/SIGN Step 1 - SABA only, Step 2 - ICS, Step 3 - ICS + LABA +/- LTRA, Step 4 - higher dose ICS (as a combination), step 5 – add on low dose daily oral steroids to high dose ICS combination

## **7.4 Themes**

Although the interview questions for participants (young adults and parents) in the near fatal studies were almost the same, the responses differ, as they offered a different perspective. The young people have lived through this experience, rather than living with a witnessed experience. Additional questions were asked specifically to the young people to gauge their understanding of asthma and who was involved in decision making at the time of the attack. In order to allow the young people to have a voice, the analysis for both groups was conducted independently, with universal themes discussed together in this chapter. Quotations are differentiated by study identification numbers, NFAYA (Near-Fatal Asthma Young Adult) for the young adults and NFA for the parents.

Throughout the semi structured interviews, participants described their experiences of living with asthma, and the impact it has had on their lives so far. They discussed the psychological and social challenges involved in living with an unpredictable health condition. They gave their views on the medications required on a daily basis, the importance of routine in achieving good adherence, and the utilisation of their asthma management plans. They reflected on the near death experience and described the impact it has had on both a personal, and family level. They provided advice for other young people, parents and health care professionals, in order to help identified ways to make improvements, and reduce risk of future attacks.

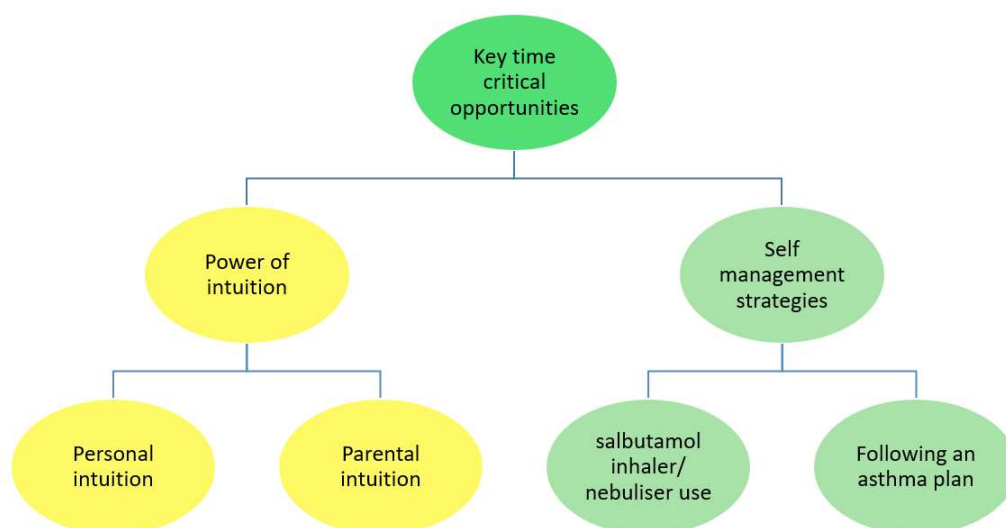
The following sections outline the main themes and subthemes which have been created through analytic engagement with the interview transcripts.

### **7.4.1 Key time-critical experiences**

Two main themes, from both parent and young adult interviews, were identified from the first aim of the qualitative study; to identify key time critical experiences in an asthma attack. These themes may offer some potential opportunities to seek medical

help at the appropriate time to prevent/ minimise risk of further deterioration leading to a possible NFA attack or asthma death. (Figure 29)

**FIGURE 29: THEMES IDENTIFIED OF KEY TIME CRITICAL EXPERIENCES HIGHLIGHTING POTENTIAL OPPORTUNITIES TO SEEK MEDICAL HELP.**



## 7.4.2 The power of intuition

Intuition is the ability to understand something instinctively, without the need for conscious reasoning (Buetow and Mintoft, 2011). Many of the parent and young adult participants discussed the power of intuition and how it influenced their decision to seek medical attention.

### 7.4.2.1 Personal intuition

Being able to recognise deterioration in asthma control during an attack can be challenging. Some of the young adult participants discussed how they had a 'gut feeling' that this attack was similar to previous severe attacks, and they needed urgent help.

*I remember I thought it was one of them [severe attacks] and then I knew in myself like I actually can't breathe, tried to tell mum that I couldn't but*

*obviously I couldn't even get the words to say, like, someone...like I need help. I remember I was trying to say, I need oxygen, because I knew at that age what it was that I needed (NFAYA05)*

*I was saying to my mum, like, it's happening again [severe attack]. And then she shouted the nurses over; last thing I remember there was about five nurses and my mum swarmed round me; and then I was back up here... [ITU]. (NFAYA03)*

#### **7.4.2.2 Parental intuition**

Some of the participants discussed how they, as a parent, or in the case of the young adults, their parent, were the ones who had a feeling something was different about this attack and knew their child needed medical review, even if it involved challenging medical staff.

*Like I think she always said she has this mother instinct or whatever but I genuinely think she just was like, no, there's something like...something's really, really not right with you and I'm just going to take you right in and someone will look at you, and then, thank God she did, yes. (NFAYA05)*

Parents gave accounts of them being the experts on their own children and often sensing deterioration or change in their own child, which was difficult to explain and was, on occasion, met with resistance from healthcare professionals. Some of the participants recognised they needed to act as their child's advocate in this situation, and felt confident to challenge some of the decision making by their clinician.

*I go with my gut..... and that's even being in the [hospital]. There was one time where my dad and I had gone in with him and a young girl came, listened to [young adult] chest and said, oh, he's okay, you can take him home. And I was looking at [young adult] and I'm thinking, he's not okay, he's really not okay. And I said to my dad, I don't think he's okay. My dad said, well if you don't think he's okay ask to see somebody else. And I said, I think I'm going to have to, I said, because I can't...you know, I can't be happy with this, he's...he just doesn't look right to me. So, she went and got this other consultant. She wasn't happy. She was...she made it very plain she wasn't happy, but she was quite young. (NFA01)*

*And I remember saying to the nurse that she needs oxygen, and the nurse was saying, yes, I just need to do this first, or blah, blah. I said, could you please just listen to me, I said, you need to go and get her oxygen. And the next thing she was on the phone. And I remember looking at her, and thinking, oh my God, why could you not just have done what I'd asked you*



*to do? But they must have their protocol, everything that they need to do, but I just remember seeing [child], and then her just sliding down the chair. And that was when she got rushed into the resus. (NFA03)*

*I knew that she wouldn't get better just with being nebulised because I've seen that level of severity before and equally, I've witnessed other attacks where we've been able to treat her at home just with spacer and salbutamol or just nebulised, hospital and then home. So, she's had all sorts of degrees of attacks so I just knew from initially speaking to her and then obviously once I saw her she was even worse. (NFA11)*

### **7.4.3 Self-management strategies.**

The use of self-management strategies during the attack was explored in detail during the interviews. Participants discussed how they, or their child, used their reliever medication and their threshold for hospital review. They discussed how using an asthma plan helped in this decision making process.

#### **7.4.3.1 Salbutamol inhaler/ nebuliser use**

Many of the young adult participants described how they used their reliever medication and how much of this medication they perceived was an acceptable amount, before thinking about getting medical help.

*Just ten puffs. Ten puffs every two hours. If I got down to about hourly stage that's when I had to think about going to hospital.... [How many doses would you take before getting help?...] I'd probably say a good getting on for a hundred (NFA03)*

A few of the parent participants discussed their interpretation of their child's asthma plan and described a plan of action to use multi dosing (10 puffs of salbutamol) at home, as frequently as two hourly. Through further discussion they perceived this plan had been developed with agreement from their child's medical team and did not feel it was excessive.

*If she's really, really poorly I've got to take her straight to A&E, I'm sure you understand that; but when she needs her inhaler more, I like to get her seen straight away after, as long as she's not going an hour, every hour. But sometimes she goes two hours and then she slumps down to*

*an hour, so I just ring them and say I'm bringing her in, and we have a plan there. (NFA05)*

A few of the participants had home nebulisers (creates a mist of medication for inhalation through a face mask) for use in an emergency, which they used in preference, or in conjunction with, the inhaler and spacer. Some of the nebulisers were driven by air and some had home oxygen cylinders to use with the nebulising unit. All of the nebulisers had been provided by clinical teams (rather than self-purchased), and participants had been provided with a plan for use whilst waiting for the emergency services to arrive.

*It was snowy, and I remember I was at my friend's house. My attacks are fast but then I get better, I bounce back fast. So, I go down fast and come back first. Then I was like, okay I'll take my inhaler and I had my nebuliser, and nothing was working. Then I remember the ambulance people coming. (NFAYA02)*

#### **7.4.3.2 Following an asthma plan**

Some of the participants discussed how they used their clinical team provided an asthma plan to help determine the right time to get help using peak flow readings, describing factors such as noticing changes in their child's ability to speak or walk, colour change (pale or bluish colour) or an increase in accessory muscle use.

Peak flow measurements were reported to be useful when making decisions about asthma severity in the home environment and a few of the participants discussed how they used them to help determine the severity of an attack, in association with other signs.

*So mum used to always...if ever I'd get unwell she'd always do my peak flow and then she'd be like, right, okay, I know I need to take you to the doctors or I need you to take into A&E. Like she would always know by my peak flow [that help was needed] (NFAYA05)*

*The peak flow would tell me if...like, I'd know my highest, and anything below that was considered a worry, and the asthma management plan would tell me what to do if it got to a certain point. (NFA03)*

Some of the parent participants discussed the changes they noticed such as colour change and how their child's behaviour changed.

*It was like her lips... She's red haired so she's got a very pale complexion, skin, but it looked like her lips blended in with the colour of her face. Her hands were a funny colour, like her nails, because I know obviously that's a sign of, you know, your oxygen levels or whatever. Her fingernails looked a strange colour. I can't even...it wasn't like they were blue, I don't think. I think they were just weird (NFA02)*

*Just very quiet, very, very quiet. Very submissive isn't the word...she becomes very resigned, so when she's really poorly it's almost as though she goes into herself. She wouldn't communicate so she would never say anything unless probably to me if she's feeling worse. But she would never converse or anything like that during an asthma attack. (NFA11)*

Another parent participant discussed how her child's first asthma attack resulted in her being unable to walk due to her breathlessness. She had been coughing throughout the day and thought to have a chest infection.

*It got to the point that [child] couldn't even walk into the hospital she was so weak, so my husband had to carry her because she couldn't breathe. (NFA04)*

The inability to speak more than one word was discussed by some of the parents. Despite this, one of the parent's reported that they still understood what their child was trying to say.

*[could she speak] ..Not really, just, kind of, what I would say was half words but I knew what she was trying to say. (NFA02)*

In some instances, parents have reported that they had followed the asthma plan but their child still deteriorated. Participants explained how they recognised their child needed medical help and despite going straight to A&E, their child experienced a NFA attack whilst in hospital.

*He started to say, Mam, I need my inhaler. And I'm like, fine, no problem; you have it. So we gave him it. I think it's about a 40 minute drive from your ma's by the time we got sorted and came back, and he was saying he needed it again. And this time, we, sort of, could see the signs, going through his asthma plan, what they'd said, his ribs starting to appear and muscle here. [points at throat] We could see he was starting to breathe*

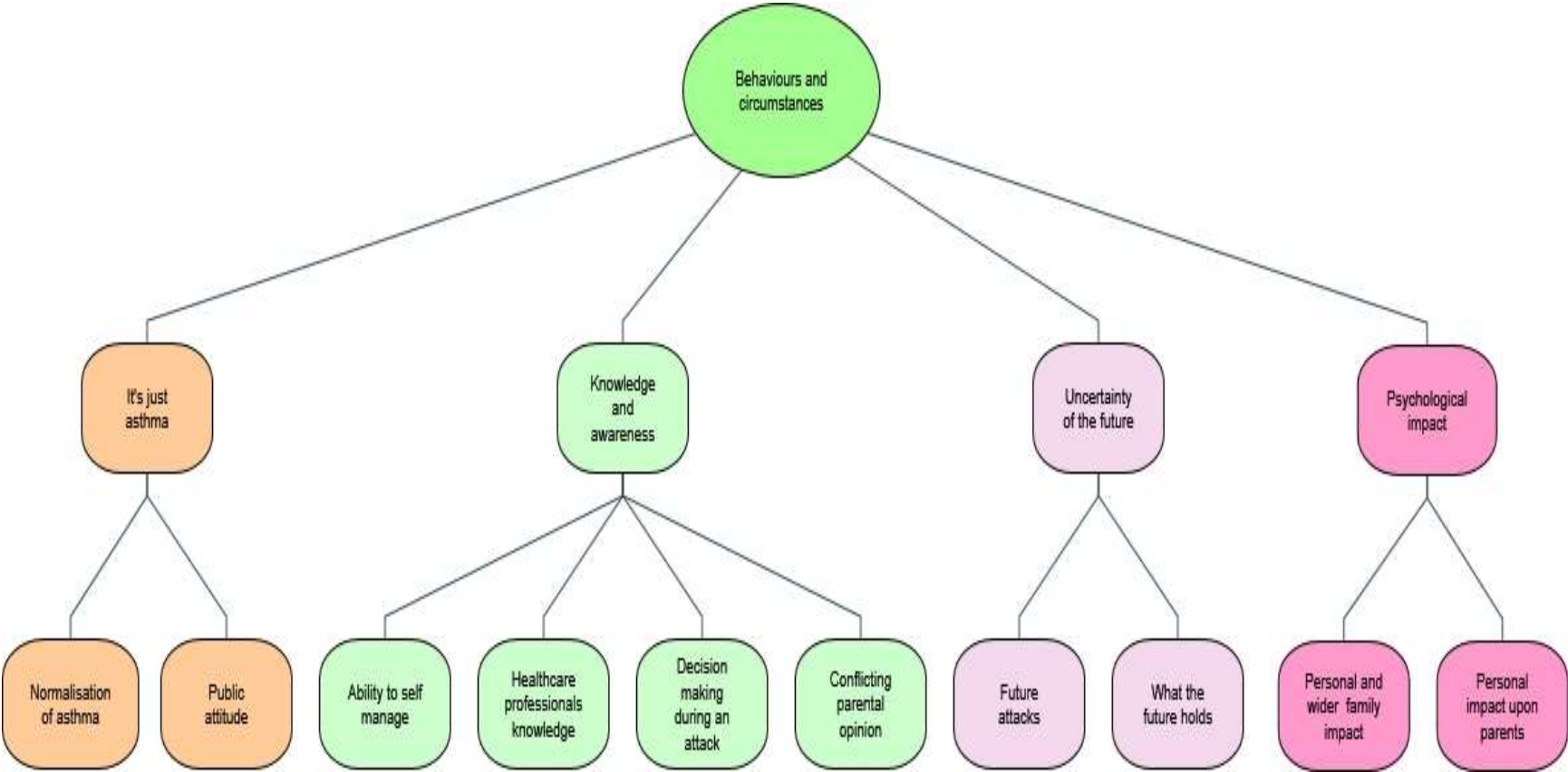
*heavily. And then I said, look, [dad], we need to go in; you know what I mean; there's no messing this time. So we headed straight back to the [hospital] and that's when everything went downhill. (NFA06 & NFA07)*

#### **7.4.4 Family circumstances and behaviours**

Considering the second aim of the study, identifying behaviours and circumstances which may contribute to an asthma attack, four main themes with subthemes were identified from the interviews with young people. They were: 'It's just asthma', Knowledge, Psychological impact and Uncertainty of the future (Figure 30).

These themes provided some context to the lives the participants had been living prior to the NFA attack, and possible factors which may have contributed to the attack.

**FIGURE 30: THE THEMES AND SUBTHEMES IDENTIFIED OF BEHAVIOURS AND CIRCUMSTANCES THAT MAY PLACE CHILDREN AND YOUNG PEOPLE AT RISK OF A NEAR FATAL OR FATAL ASTHMA ATTACK**



#### **7.4.4.1 'It's just asthma'**

Many of the young adults had been diagnosed with asthma in early childhood and had no recollection of life before asthma which could make it difficult to recognise variance of deterioration outside their experience. Asthma featured in all the young people's lives, but the influence the condition had on their day to day lives appeared to differ depending on asthma severity.

*I think she said I started symptoms when I was four months but obviously I can't remember when I was, kind of, you know, diagnosed with it or anything like that. It's just been a constant through my life. (NFAYA01)*

*I think I was under one. So, I've had it for a long time. (NFAYA2)*

*I have had asthma since I can remember. I think I was diagnosed when I was 1 (NFAYA4)*

#### **7.4.4.2 Normalisation of asthma**

Living with a long term chronic health condition, some of the young people appear to have accepted asthma symptoms and asthma attacks as normal. This can add additional challenges in changing mind sets and expectations so young people can aim for good asthma control and zero tolerance towards asthma attacks.

*Actually in 2009 I never got admitted. And then after that I went back to normal [having an attack] (NFA3)*

*It was just like a normal, kind of, what I'd describe as an everyday asthma, everyday asthma attack as if that's a normal thing. It was just like a normal thing (NFAYA01)*

*I think I've been in a coma three or four times. It's just normal now. It's normal to me and that's mental. See to some people, that's life changing but to me it's normal. (NFAYA03)*

#### **7.4.4.3 Public attitude**

Participants discussed the fact that asthma is a common condition and reported feeling that the severity of their condition, or child's condition, was not taken seriously by those around them. Most of the participants shared experiences of family

members, friends or school staff lacking awareness of the risks associated with having an asthma attack.

The young adults explained that,

*Because everyone knows at least one person with asthma, it is not taken seriously enough (NFAYA04)*

*I think it's very underrated. Cancer gets a big thing made about it whereas asthma is like, take your inhaler. I'm like, if it's that easy then I'm pretty sure half of the stuff wouldn't have happened, to all the other people too because quite a lot of people have it. But obviously not all as bad as some people. (NFAYA03)*

This was supported by the adult participants.

*Because like I say, because you think, well, it's just asthma; it's like, it's not even serious. (NFA06 & 07)*

*I think there's a big ignorance towards asthma. People just think, oh, you get a blue inhaler and you puff on it every so often. (NFA02)*

#### **7.4.5 Knowledge and awareness**

Knowledge and awareness within this theme is twofold, and relates to the knowledge of both parents/ patients and healthcare professionals

##### **7.4.5.1 Ability to self-manage**

Self-management of asthma on a daily basis empowers the patient or care giver with the knowledge and skills to respond to situations which may trigger an attack, and adjust medications to prevent attacks. Within this subtheme, many of the participants discussed their trigger factors for attacks, adherence with preventative medication and the ability to recognise symptoms, and respond accordingly. Some of the participants discussed the challenge of care being delivered by separated parents and how their opinions were often conflicting.

##### **Identification of trigger factors**

The ability to recognise trigger factors for an asthma attack was important to help limit exposure if triggered by an allergen, or to have a plan in place at the onset of a viral

trigger. Although a few of the participants were allergic to cats or dogs they believed they could tolerate living with their own pet.

*Yeah, sometimes it's quite obvious things, you know, exercising, reactions to hay fever and sometimes, you know, just general stress things but then there's obviously other times where it's harder to pinpoint what a cause was. Sometimes it can be weather changes or it can be anything really to be honest. (NFAYA01)*

*Colds, change in the weather, oh, definitely. If it goes from warm to cold and vice versa, and if it goes from...smoking as well... She was in July, she'd gone away with her school and somebody was caught smoking in a toilet ...(NFA05)*

*Yes, hay fever, animals. Not my animals. So, I'm used to them now. When I first got my dog, I didn't get wheezy at all whereas at other peoples' I did. I just got itchy with him, but I eventually got used to it. But, animals, the weather, sports. Anything. The cold, the flu, even just drinking diluted orange juice. That irritates me, and I don't know how but it's just mental, all these wee things. (NFAYA02)*

### **Adherence to preventative medication**

Preventative treatment for asthma is required on a once or twice daily basis, even when well, to control asthma symptoms and minimise the risk of attacks. All of the participants discussed how this could be challenging at times. The young adult's admitted they often forgot doses of medication, some more than others, although a few said they rarely forgot.

*So my routine is hard to coordinate with preventative measures and stuff like that (NFAYA01)*

*Then after you get into high school and you're doing things like having sleepovers with your friends and you're a bit more independent my mum obviously used to rely on me to do it myself and then I obviously got really lazy with it, like when I thought I was fine I didn't think I would need to take my inhaler. It wouldn't be until that I got unwell that I was like, okay, I'll take my purple again, but I should have been taking my purple every single day. (NFAYA05)*

*Because I'm so used to it. They're part of my life. I sleep with my inhaler in my bed and if it's not there I feel like I'm naked. Sometimes I'd forget now and again but nothing major. (NFAYA02)*

*I went through a period of missing them a little bit; it was more during school, I'd wake up late. That's why I moved my inhalers bed side, so I could just wake up and take them, then don't worry about that any more.*



*So now I just keep that in the car and take that when I'm going to work; and that's all I have to do now [once daily Relvar] (NFAYA03)*

Many of the parent participants discussed the need to constantly remind their child to take their medication and how they often supervised them.

*Last year we moved the medicines into [child]'s room, so she's got her own medicine bag. Don't get me wrong, there's always a bit of a rush in the morning. She's not the greatest at getting up in the morning, so it's one of the things I always ask her before we leave the house, did you take your medicine? 90 per cent of the time she'll go, yeah. 10 per cent of the time she'll run back up the stairs (NFA04)*

*She's totally compliant with her drugs. I do assist her taking her drugs so that I'm happy that she's taking them but she does take them anyway, she's very good. (NFA11)*

*I think we were quite lucky in that he really was pretty good at taking it. We didn't have a lot of the kind of, you know, I'm not dealing with this, I'm not taking it, and stuff like that. I mean I'm sure he had his moments but most of the time he was generally okay (NFA01)*

### **Ability to recognise symptoms, adjust treatment and get help**

Parents reported the ability to recognise symptoms as they occurred and adjust treatment as an important component of self-management. The majority of participants had an asthma plan and they discussed how these plans were used to adjust treatment in response to the severity of symptoms with some using peak flow monitoring to assist with this. Parents had acquired skill and expertise over the years managing their child's asthma. Parents perceived this knowledge allowed them to control their child's asthma. This expertise was also acknowledged by the young adult participants.

*She's so good. Like, if she's not feeling right, she'll go through the process of increasing her inhalers, she does that first, and then if that doesn't work, maybe say, after three or four days, then she'll phone the doctors, make an appointment, and then she'll say to me, mum I've got a doctor's appointment, I'm not feeling that great. (NFA03)*

*We did notice her mood dropped a little and I've never noticed that before. Her mood, kind of, dropped a little bit. She was a bit nippy, you know, and that's not like her and within a few hours she showed signs of that she*

*needed to have her steroids and start multi-dosing and whatever because obviously her peak flow had gone down. (NFA02)*

*[asthma control] Will be monitored through a peak flow, and the peak flow would tell me if...like, I'd know my highest, and anything below that was considered a worry, and the asthma management plan would tell me what to do if it got to a certain point.... if it was below 400 for two days I'd have to come into A&E and get admitted. (NFAYA03)*

#### **7.4.5.2 Impaired decision making during an attack.**

A few of the young adult participants also discussed the difficulties in decision making during an attack, presumably due to falling oxygen levels (hypoxia) and panic. They found it hard to be rational in their thought processes and the everyday task of taking their inhaler became difficult.

*When you're having one it's like your brain is getting squished, all the air and oxygen...and I'm like, I can't do it anymore. Then sometimes I do pass out because it's too much for my head. (NFAYA04)*

*I couldn't get my breath and I was struggling to get the inhaler to work, so I started banging on the doors and the wardrobes to try and get somebody to come in – it's about three in the morning, something like that – then Mum came rushing in, put the light on, got me in a better position to take my inhaler, got us to calm down. (NFAYA03)*

#### **7.4.5.3 Conflicting parental opinion**

A few of the parent participants were single parent families (n=3/10). There was an apparent difference of opinion and attitude towards asthma and asthma management from the perspective of the parent the young adult lived with (their mother in all cases) and they did not feel that their father took it as seriously as they did.

*He didn't take her asthma seriously. And, I don't think he saw it as an illness, although his dad's a chronic asthmatic, and a couple of his uncles as well, have got asthma, and his mum, so he knew how serious it was, but just with [child], he just never took it seriously. and [dad] would just say, you're being stupid you know, she's fine. Well no, [dad], she's not fine, because you know what's going to happen if we didn't try and prevent it going right into your chest. But with him, it was just always a fight. (NFA03)*

*So, dad's girlfriend had a dog that she was really allergic to, so we had a bit of a conflict there because I think it was suggested that stress may play a part in her exacerbations. But I knew that it was the dog that was making*

*her poorly so that was quite a trying time. My ex-husband also suggested that we got a dog because he thought that it might make her immune to things that she was allergic to...[the mum then got a dog] I think she had an asthma attack every week until . So that was quite interesting, that was all down to dad (NFA11)*

Two of the young adults also came from single parent homes (n=2/5) and reported how they felt less confident being cared for by their dad.

*I remember I'd always get more paranoid if I was at my dad's and I was unwell. Whenever I'd go to sleep I'd always like get nervous before I'd go to sleep because my mum wasn't there because I always thought she knew...she knew me better in terms of being unwell but I think if I was unwell my mum would be like, no, you're just staying with me, you're not going to your dad's, but there was a period of time when I was like nervous at my dad's house unwell. I'd always make sure my inhalers were like right at my pillow and I knew where everything was because I always thought it would have to be me that would handle it if anything did happen, not my dad. No offence to him but, yes, it was always definitely my mum that knew more what was going on. (NFAYA05)*

#### **7.4.5.4 Healthcare professionals' knowledge and awareness**

Some of the participants discussed how they felt some of the clinicians were unsure how to manage an acute attack and did not always listen to them.

*She was just back to back nebs but I pointed out that she'd been on back to back nebs from about half five and it now getting slightly ridiculous that she wasn't being...there just didn't seem to be any meaningful review. I didn't feel anyone was spending enough time with her, I could see that she was deteriorating before my eyes. I actually phoned [another hospital] at one point and asked them to speak to the hospital because I didn't feel that she was getting the care that she needed. (NFA11)*

*I do think doctors are great. I'm not trying to say it was the doctors but every time we were told something different whereas maybe if we went to a doctor that knew asthma really, really well when I was unwell for the first time, they'd be like, okay, I'm going to give you this [oral steroids] the last time I was at the doctors I actually told him, I was like, no, you need to give me steroids. I know my body. I know it's the only thing that's going to help it. He was like, well, you have had asthma all your life, I trust you, and that's the only reason he gave me the steroids was because I was like, no, I know, I know what's happening inside. I need these steroids. He was like, well, okay, then. (NFAYA05)*

Some also stated how no one had ever discussed how serious an asthma attack could be, and were unaware it could result in death.

*Nobody that gave any healthcare to [child] ever told us that. I had heard of a story of somebody years ago but you don't think...well, you don't think your own child come could as close to that happening. I don't know why you don't think that because obviously anything can happen to anybody but, yes, I don't think people are aware enough how severe asthma can be. (NFA02)*

*I don't think many people are aware of that [you can die of asthma] and I think kids with asthma no matter how like severe it is should be told that and then they might actually think, okay, well, I'll start remembering, I'll remember myself to take my inhalers every day and I'll make sure that if I feel unwell I tell my mum or dad or things like that because if they're aware that that can happen it might scare them a little bit and then sometimes if they are scared they'll take it more seriously. I think that could probably prevent a lot of like whatever happened to me. I don't know if it happens a lot but I think that could prevent that from happening because people would take it more seriously, yes. (NFA11)*

#### **7.4.6 Psychological impact of a near fatal asthma attack**

The third aim of the qualitative study was to understand the long term consequences of a NFA attack. Asthma attacks are frightening and many of the participants talked about how they, or their child, often become worried or anxious each time they had an asthma attack. The impact of having a NFA attack however seemed to have a more profound impact on the young people, parents and other members of the family. Access to a Psychologist appeared to vary amongst participants, however many of the participants acknowledge that psychological help would be useful, if offered. The subthemes of personal impact and the wider family impact (young adults) and personal parental impact were identified within this theme.

##### **7.4.6.1 Personal Impact and impact on the family**

All of the young adult participants discussed the personal impact the NFA attack had on them, which included anxiety and changes in personality. The attack had changed their outlook on life, and highlighted their concern for both their families and themselves. The subject of post-traumatic stress disorder (PTSD) was raised on a few occasions, however the participants did not believe they suffered from this condition.

## Personal impact

*I would just say I'm a bit more paranoid whenever I do get unwell now. I overthink everything because I just think back to then, like, oh, but what if it happens again? I didn't realise how serious it was, maybe I should be a bit more cautious. Yes, definitely a bit more cautious and paranoid now. (NFAYA05)*

*Since the attack I haven't been myself at all. I take life more seriously and I am so grateful that my mum and my sister were with me at the hospital because if they weren't I would not be here. I wasn't treated well at [place] hospital at all, it scares me to think that my attack was near fatal, I had never felt like that before. I never want to feel that way again. I often think of my experience and it makes me upset, I could've died. The attack stops me from doing the things I love, because I never want to feel the same way I did. (NFAYA04)*

*Some days I can't get out of my bed and I just feel that shit about myself, but she thinks I'm being lazy. I'm like, no I'm having a bad day. Because they've not been through it, they don't really understand but really I don't expect them to understand. (NFAYA03)*

## Wider family impact

The young adults discussed the impact their attack had on their parents and siblings.

These family members had watched a traumatic event where it initially appeared that the young person had died.

*It affected them [my family] quite a bit, my mum especially. To put it in her words that she'd aged ten years. [an appointment was offered with a psychologist] I could see why they would have, like, I admit it, and they said that apparently it can cause PTSD, they said; but I just felt all right in myself, so I just moved on (NFAYA03)*

*I spoke to my parents a bit but I was more worried about them because I felt, I don't know, I felt, like, they'd seen an aspect that was worse than what I experienced. They saw their son die and be unresponsive and have to do, you know, crazy dramatic things to resuscitate me, I guess, whereas I was out of it and I was up again. So, for me it was not as traumatic for me as it was for my family I think and I think that's just, because if it was [brother] having the attack and I was in the position of [brother] I would feel helpless and I would feel completely out of control and I would prefer that to be me than vice-versa. (NFAYA01)*

### 7.4.6.2 Parental impact

The effect of witnessing their child having a NFA attack has had a significant impact on the parent participants, not only immediately following the episode, but also long

term. In the previous sub theme of wider family impact, this was discussed from the perspective of the young adult however, this subtheme gives greater insight into the personal impact this attack had on the parent participants. Some of the parents who had recently experienced the event, found it difficult to sleep for fear of not hearing their child through the night.

*The GP give us antidepressants because I'm not sleeping but then again I wouldn't take them in case I fell into a deep sleep and didn't wake up if she was coughing. You can't win. I'm vigilant all the time. I don't go to sleep until about four or five o'clock in the morning and then I'm up for 7.00am for school and I don't sleep at all. I feel like a zombie. (NFA08)*

*[Dad] We don't sleep a lot. [mum] No, constantly listening, aren't you? Constantly listening, going in his bedroom, checking up on him. If you are up at the toilet through the night, you know, stand at his door listening. [dad] Door, listening. Or I'm going in, and just having a look at his chest to see how he's breathing, and things. My daughter was coughing the other week, and I was like, oh, is it him? Is it her? Which one is it? (NFA06 & 07)*

A few of the parents who had witnessed the event more than five years ago, could still vividly recall the experience, which stirred a lot of suppressed emotions.

*We've all suffered for it, but my husband probably was the one who suffered worst because he actually saw it. I was out of the room at that point when [young adult] went down. But my husband didn't realise maybe to begin with the kind of post traumatic stuff he was dealing with. If there was a bang in the night the two of us were out of bed like lunatics standing there going, oh, you know, because we...because that's what happened that night, you know, that we were up and not knowing what had happened and we were walking into wardrobes in the dark trying to work out what had gone on, you know, with the bang, and stuff. (NFA01)*

*[the near fatal attack] affected us greatly. My husband is a worrier, I am the strong one in the relationship. Here's me after just having a bubble there a minute ago. [Dad], very strong, manly and can fix just about anything, but mental strength he's not as strong as me. He would just worry all the time. Worry, worry, worry. (NFA04)*

#### **7.4.7 Uncertainty of the future**

Participants realised the seriousness of the attacks which either they, or their child, had experienced. They discussed their concerns about future attacks and their concerns for the future.

#### 7.4.7.1 Future attack

Some of the young adult participants expressed their fears about a future NFA attack and the possible outcomes, which included hypoxic brain injury or death. A few of the young adult participants felt like they would not be able to cope with another serious attack, which could potentially affect how they respond to an emergency situation again in the future. One participant expressed how he would rather die if he had this type of attack again, preferring not to relive the long and difficult period of rehabilitation post NFA attack.

*If it happens again, I don't want to come back. I wouldn't want to go through all of that again. My gran was like, you did it once. I'm like, but I'm not doing it twice. It would be too much for me. (NFAYA02)*

Previous experience of medical care which fell below expectations led to a feeling by a young adult participant that a similar experience would increase the risk of dying of an attack in the future.

*I worry more often about having asthma since this attack due to how I was treated. Before this attack I thought that I would always get sorted out at hospital, but after [hospital], I understand that one day I will have an attack that I can't be saved from. (NFAYA04)*

A few of the young adult participants discussed how they would mask symptoms of a future attack in their adolescence, as they did not want to worry their parents. They had an appreciation now that they are older, that this action would have caused more stress and anxiety to the parent.

*But because of the way it affects them is the reason why I'd sometimes try and hide it. And it was a bit silly, when I think about it, but I just didn't want to...I'd, like, try and control it myself, because I knew what would, like...trying to suppress my asthma, but then I didn't want them getting stressed over it as well, so I'd try and control it myself; which didn't work a lot of the times. (NFAYA03)*

#### 7.4.7.2 What the future holds

Young adults and parents discussed the impact of a previous NFA attack and living with asthma had on their/ their child's ability to live independently and future career

prospects. Some of the parents discussed how they expected their child to live with them permanently, due to the effects of the hypoxic brain injury caused by a NFA attack.

*I can't see him moving out. He needs us. He wouldn't survive on his own [mum] just doing medication and stuff for him [dad] NFA 09 &10*

All of these variables had a perceived impact on the well-being of the young people which could have an influence on their mental health and resilience in the future. The anxiety experienced by some of the young adults made it difficult for some of them to be alone, preferring to have constant companionship, even if it was virtually via the internet.

*I avoid it pretty much as much as possible [being alone]. I've not been in a situation where I'm alone, even to go uptown, I don't really go uptown on my own, someone is usually there, my wife or my brother or parents or whatever. The only time I'm ever really alone is if I'm driving back from somewhere, like dropping my wife off at work or something like that, you know, or even if I'm alone I'm talking to someone, you know, I play x-box, I have a headset on, so I'm never really alone where I feel, like, I'm helpless, kind of, thing. (NFAYA01)*

The effects of living with asthma and previous school loss, had an impact on career choice and long term prospects, with reports of some of the young adults not achieving their possible true potential.

*I work in a warehouse making kitchens, assembling them, and currently in the process of trying to work a way of fitting kitchens; and that's obviously it'll do a lot of dust, so it's not ideal, so it probably wouldn't have been where I saw myself going, with having asthma. (NFAYA03)*

Some of the parents realise that as their child gets older, they will not always be with them in the event of an attack. They felt it was important to try and encourage their child to be able to convey to medical staff how they felt in the event of an attack.

*I've had to discuss [future attacks]...she also said but you'll always be with me, won't you? I've to discuss that, no, I probably won't always be with her and that she would possibly have to go into other hospitals. I've tried to have a discussion with her that she needs to actually vocalise how poorly she feels and she needs to know herself how quickly she deteriorates and she needs to be able to speak to a medical professional*



*about how poorly she is. Because at the moment I do that for her which I don't know whether that's a parent thing or because she just doesn't do it herself. (NFA11)*

## **7.5 Conclusion**

In this chapter, I have presented findings from the 15 semi-structured interviews undertaken with parents and young adults, exploring their perspective of a NFA attack, in response to the first three aims of the qualitative study. The themes identified as key time critical events around the time of the event, which included the power of intuition and use of emergency medication, may offer clinicians some topics to consider during a consultation with children and their families when discussing asthma attacks, and the appropriate time to access medical assistance. The behaviours and circumstances which were identified may offer clinicians some insight into a number of factors which affect parents and children on a daily basis which include the psychological impact of living with asthma, and fear of future NFA attacks. These behaviours and circumstances will be discussed in chapter nine and will address the fourth aim of the study.

## **7.6 Summary and next steps**

In this chapter, I have presented findings from the 15 semi-structured interviews undertaken with parents and young adults, exploring their perspective of a NFA attack. In the following chapter, I will present the findings from seven interviews with parents on their experience of their child's fatal asthma attack.

## **8 Chapter Eight: Findings from the interviews with parents on their experience of their child's fatal asthma attack.**

### **8.1 Introduction**

The previous chapter outlined the findings of the interviews with parents and young adults on their experience of a NFA attack. The same theoretical framework and process for analysis as the near-fatal asthma study was used. This chapter reports the findings of seven semi-structured interviews with parents affected by their child's death as a result of an asthma attack, to address the aims of component two of my study. It also includes details of participant characteristics. Quotations are provided in support of the constructed themes and subthemes.

### **8.2 Participants.**

Seven parents participated in semi-structured interviews. In addition to the participants who took part, another three parents made enquiries about the study and asked for information to be emailed. Information was sent, however they did not reply to two follow up emails, therefore no further contact was made. It is impossible to know the number of potential participants who read the study information, and this will be discussed further in the next chapter. Interviews lasted between 27 minutes and 76 minutes. Additional time was spent in the family homes looking at family photos, home videos and one occasion visiting the graveside of a child. All participants had been affected by asthma related death within the last ten years. The characteristics of the participants are displayed in Table 52. All the participants were mothers, however I did meet some of the fathers before the interviews commenced. One of the fathers explained that it was too raw and painful for him to relive the event, however he was supportive towards the research topic. The interviews took place within the family home (n=6/7) or at a local community venue (n=1/7). The one participant who chose a local community venue later explained that her son, who had

autism, disliked strangers within his home environment. Although the age of the participants' children ranged from child to young adult, the term child will be used to represent them all. To support family confidentiality, children's ages are provided within a three year range. Ethnicity is also excluded from this table as there was a concern that ethnicity combined with other demographic information would make participants identifiable.

**TABLE 52: CHARACTERISTICS OF THE PARTICIPANTS IN THE FATAL ASTHMA INTERVIEWS**

| Participant number                                | FA01          | FA02          | FA03          | FA04      | FA05          | FA06          | FA07          |
|---------------------------------------------------|---------------|---------------|---------------|-----------|---------------|---------------|---------------|
| Gender of participant(s)                          | F             | F             | F             | F         | F             | F             | F             |
| Gender of child                                   | M             | M             | F             | M         | F             | M             | F             |
| Age bracket of child at time of Fatal attack (FA) | 10 - 12 years | 19 - 21 years | 13 - 15 years | 7-9 years | 19-21 years   | 10 -12 years  | 13 - 15 years |
| Time since FA                                     | 4 years       | 2 years       | 6 years       | 10 years  | 1 year        | 10 years      | 4 years       |
| Location of FA                                    | Community     | Community     | Home          | Home      | Home          | Community     | Home          |
| Place time of death was declared <sup>9</sup>     | ICU           | ICU           | ED            | ED        | ED            | ED            | ED            |
| Onset of fatal attack (gradual or sudden)         | Sudden        | Gradual       | Gradual       | Gradual   | Sudden        | Sudden        | Gradual       |
| BTS/SIGN step                                     | 4             | 3             | 4             | 2         | 1             | 2             | 5             |
| Geographical location                             | North England | North England | Scotland      | Scotland  | North England | North England | North England |

<sup>9</sup> Place time of death was declared – Intensive Care Unit (ICU) were the decision was made to switch off ventilation due to brain stem injury. For those declared dead in the Emergency Department (ED) active resuscitation was maintained by the Paramedics until they arrived in the ED where a Doctor pronounced the time of death.

### **8.3 Themes**

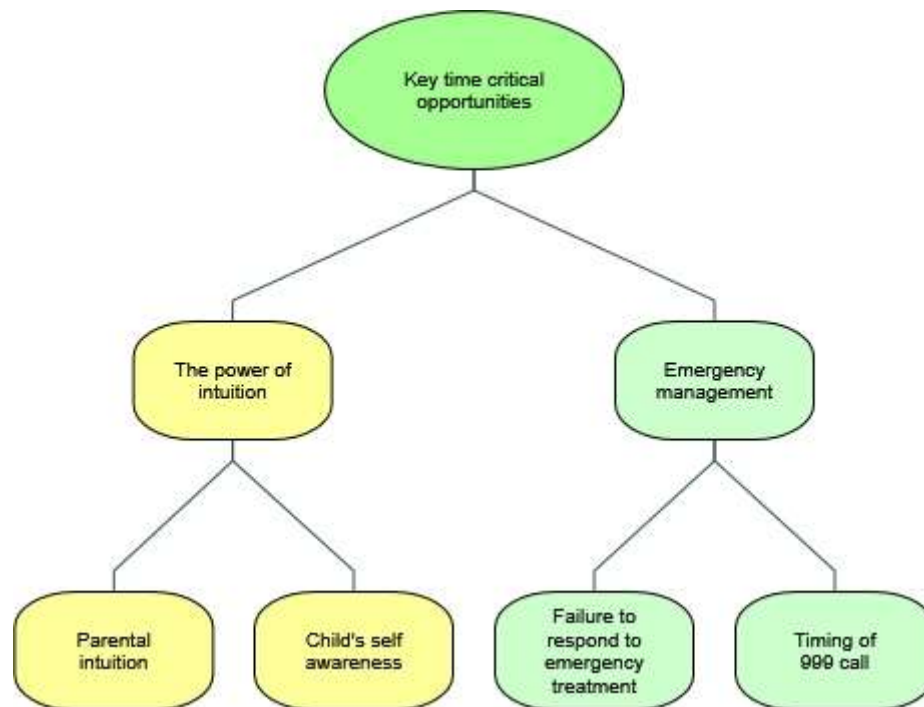
Throughout the semi-structured interviews participants shared their experience of their child's asthma from diagnosis until death. They discussed the daily routines of their child taking medication, and the need to avoid asthma triggers. They shared details of previous asthma attacks and how they had been managed. Living with a long-term condition, they discussed the physical, social and psychological impact of asthma on both their child and family. Participants also offered advice for healthcare professionals in order to identify ways to make improvements for those affected by asthma to reduce risk of attacks and asthma deaths. The interviews all followed a similar structure, with participants initially providing information on the impact of asthma on their child's life. I then used the same question in all interviews, which indicated we would be moving on to talk about the final event, "do you feel ready to move on to talk about the final attack?"

The following sections outline the main themes and subthemes which have been created through analytic engagement with the interview transcripts.

#### **8.3.1 Key time critical experiences**

In the previous chapter themes were identified which may offer opportunities to seek medical help at the appropriate time to prevent or minimise the risk of further deterioration, leading to a near-fatal attack or asthma death. In this chapter the children have died as a result of their attack, however two main themes have been identified within these interviews, which may offer guidance for clinicians during consultations and educational events, to help raise awareness of possible signs to observe for during an asthma attack, which may help reduce the risk of death (Figure 31).

**FIGURE 31: THEMES IDENTIFIED OF KEY TIME CRITICAL EXPERIENCES HIGHLIGHTING POTENTIAL OPPORTUNITIES TO SEEK MEDICAL HELP.**



### **8.3.2 The power of intuition**

This theme was previously identified within the NFA attack study. Participants shared their experiences of instinctively knowing something was different about their child on the day they died and that help was needed urgently. They also shared final words from their child, which may also be indicative of a similar instinct. The subthemes of parental intuition and child's self-awareness were identified.

#### **8.3.2.1 Parental intuition**

All of the participants were parents of children who had died from asthma attacks and some of them described how they felt something was different about how their child looked or behaved which was unusual for them but not necessarily specific to an asthma attack.

*.... And I could see (name)'s face, he just... Thinking back now, he didn't look right, he looked terrified. He just couldn't breathe... And I just...I knew..* (FA01)

*And I said to (name), before I left, just keep an eye on her, I think she's okay, but I just, there was just something about her look, and I couldn't pinpoint what it was.* (FA03)

*So I had been admitted to hospital because they were doing tests and the night (name) died I discharged myself from the hospital, but I don't know why.... I needed to get home.* (FA04)

#### **8.3.2.2 Child's self-awareness**

Some of the participants discussed how their child told them they felt unwell during the attack, or just leading up to it, with specific symptoms such as the inability to breathe and the feeling they were going to die. It is difficult to distinguish if this was a different feeling from previous attacks, or specific to this final attack. Other participants mentioned how their child said they felt different with non-specific symptoms, such as not feeling well, having a headache or feeling clammy (which may have been coincidental) or warning signs of hypoxia (headache) and or falling blood pressure/ peri arrest (clammy).

*He's like, no, I can't breathe.....And he went, I need an ambulance, mum..... And he looked at me and he asked me if he was going to die.* (FA01)

*He said to his friend that he couldn't breathe properly....He just said there and then, I don't feel well.* (FA02)

*She said, oh I don't feel well at all mum, I feel really...she was very clammy.* (FA06)

#### **8.3.3 Emergency management**

During the final attack, all of the participants discussed how their child was using reliever medication. They spoke of how this medication did not appear to be relieving symptoms and their child was continuing to deteriorate.

### 8.3.3.1 Failure to respond to emergency treatment

For the younger children they were receiving this through a spacer whereas the young adults were using a metered dose inhaler alone which would have affected the amount of medication deposited into the airway. One of the participants used a home nebuliser driven by oxygen as part of their asthma plan. This had been provided by their clinical team having previously experienced a NFA attack. The participants talked about their child not responding to treatment which prompted a call to the emergency services from either the parent or another adult (grandmother, friend etc.).

*He was like, I've given him his inhaler, he's had it about four times but he's not getting any better..... I said, we've got to give you it at least six more times. I said, but we'll ring an ambulance for you.....I told my friend to ring the ambulance while I was sorting him out, and he was just getting worse. (FA01)*

*[name] had got his inhaler out of his pocket, tried the inhaler and said that it's not working..... So his friend rang an ambulance, rang 999, and drove him to the nearest health centre to get help. (FA02)*

*She was on the bed, breathing [on home nebuliser]. And I just sat next to her, 'cause I always sat next to her, but put my arm behind her and not restricting the front. And I used to always rub her back. And I said, you're tight again and she was just 'Yes' [forced]. Fighting to get it out and I just looked at the machine and when I looked I could see her oxygen levels had dropped to 83 per cent at this point. So I knew it wasn't good. (FA07)*

Inhaler technique was not discussed during the interviews. One of the participants however spoke of how her child had inadvertently fitted a canister of salbutamol with an incompatible holder. This may explain why he perceived his reliever inhaler was not working during his final attack.

*So (name)'s canister, one he normally had, was a small blue one, but his canister had been put into a very tall dark blue holder. So we always thought that when (name) said that it wasn't working, that it didn't work because it wasn't relieving, he was struggling breathing, but in fact it wasn't working because it wouldn't press down. So whether that would have made a difference to what happened, I don't know. (FA02)*



### 8.3.3.2 Timing of 999 call

The response time for an ambulance crew to respond to a call for a severe asthma attack is between seven minutes (category one) and 18 minutes (category two) however times are variable due to geographical location and service demands (Nuffield Trust, 2021). All the participants had either made the call for an ambulance if their child was at home, or another adult had for those who had an attack in the community. Emergency treatment was initially instigated using the reliever inhaler or nebuliser, and once it was perceived to be ineffective, an ambulance was called. None of the participants reported an excessive<sup>10</sup> use of salbutamol before calling for help however all of the children were exhibiting signs of a NFA attack (in cardiopulmonary arrest or cyanosed) by the time the paramedics arrived. Five of the children subsequently died out of hospital. The other two children were in cardiopulmonary arrest when the ambulance crews arrived, they were intubated and ventilated at the scene and taken to hospital. Due to the period of time they were hypoxic they suffered from a hypoxic brain injury and brain stem death, resulting in withdrawal of all medical care.

*The ambulance took 13 minutes because of traffic. The first responder and the ambulance arrived at the same time, but, by that point, (name) had already been down eight minutes and he was in full cardiac arrest when they got to him. (FA01)*

*Well, a first responder arrived first, and then the ambulance; and I think it was .... I think it was about seven minutes, six, seven minutes they were there; they were there really quick. They had reported that (name) was cyanosed, which is blue, isn't it? (FA02)*

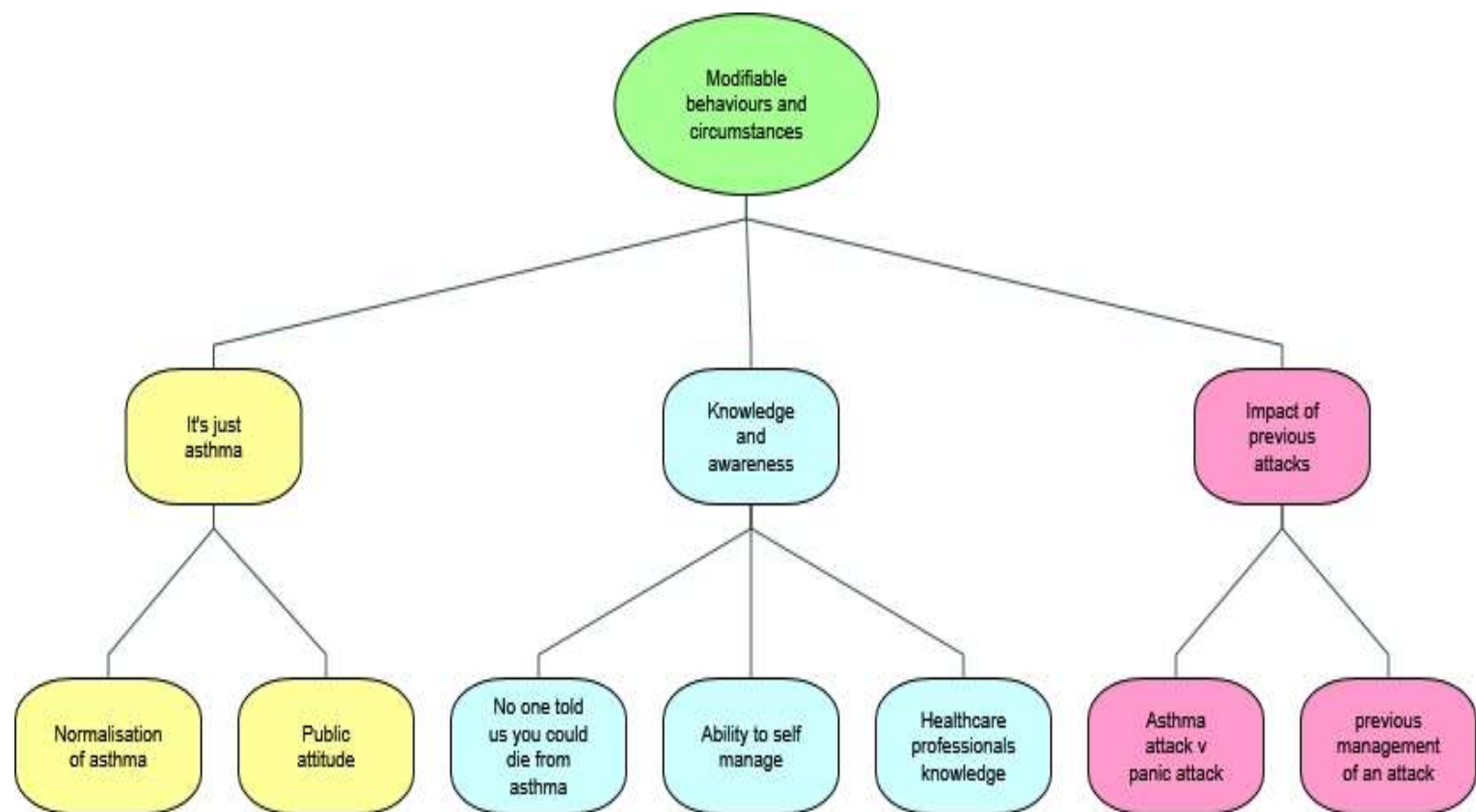
*By the time the ambulance came, she was just jumping, her whole body. I didn't know it was cardiac arrest, I didn't know, 'cause I've never seen it. And I just didn't know what was happening, 'cause her whole body was shaking. (FA03)*

<sup>10</sup> Excessive SABA use would have been more than the recommended dose according to the emergency zone in the participant's child's asthma plan.

#### **8.3.4 Potentially modifiable behaviours and circumstances.**

In the previous chapter findings were presented which identified family circumstances and behaviours that may place children and young people at greater risk of a NFA attack. In this chapter, themes have been created from the interviews with bereaved parents which could offer clinicians greater insight into the events surrounding a fatal asthma attack, to address the second aim of my study. Three main themes with subthemes were created: 'It's just asthma'; Knowledge and Awareness; and Impact of Previous Attacks are presented in Figure 32.

**FIGURE 32: THE THEMES AND SUBTHEMES CREATED OF POTENTIALLY MODIFIABLE BEHAVIOURS AND CIRCUMSTANCES THAT MAY PLACE CHILDREN AND YOUNG PEOPLE AT RISK OF A NEAR FATAL OR FATAL ASTHMA ATTACK**



### 8.3.5 It's just asthma

Many of the participants discussed how their child had lived with asthma for many years and how it was part of everyday life. They also discussed how asthma was generally perceived by the general public as a condition that is easily treated with a reliever inhaler.

#### 8.3.5.1 Normalisation of asthma

Some of the participants spoke of how their child had been diagnosed with asthma in early childhood and had no recollection of life without it. They discussed how mild symptoms were accepted by their child as their normal, and that often they needed to be prompted to take their reliever inhaler to prevent further escalation in attack severity.

*Because I think, because she'd had it for all her life, it was part of her, and it wasn't something that she got when she was seven, and she was scared of. She'd lived with it all her life..... A lot of the times, I would say to her, you know, is your asthma bad – no, it's fine, it's fine, I'm fine, I'm coping. And she, I think she didn't like to give into it. I think she didn't want it to beat her. And if she had somewhere to go, she wanted to go there. (FA03)*

Some of the participants spoke about their attitude towards their child's asthma and how they did not perceive it to be a serious condition, rather just a condition which caused symptoms, which would go away after taking the reliever inhaler.

*Nothing's going to happen and the amount of times when I think back if (name) was having a bad night and he was a bit wheezy and...I want to say crabbit, a typical wee boy, huffy, crabbit like. Och, it's just your asthma, there's nothing wrong with you. (FA04)*

*.... because I did used to think, you know, sit down, (name), have your inhaler; and he'd be okay. So you think that that's what it's going to be like all the time; sit down, calm, take your inhaler. (FA01)*

### 8.3.5.2 Public attitude

Many of the participants discussed how asthma was a condition that the general public, including other family members, friends and school staff, did not take seriously. This general lack of awareness may place increased risk upon a child or young person, as there may be a delay in realising the urgency of calling for help in the event of an attack, which is not responding to treatment.

*They just seemed to be really ignorant but... It's difficult to explain to people. You know, like when you say people are ignorant, and it sounds really offensive and I don't mean it as offensive, they just... They were just blasé to it and they don't appreciate that even people that have asthma around them, they just don't appreciate how bad it can be and they just think that's all right, they'll be fine in a minute. And it's really not like that, so it does wind me up. Even now, it frustrates me when I see it or hear about it..... Or the family's, oh yeah, he's got asthma he's fine, just give him that and he'll be alright in a minute. (FA01)*

*I think now they need to take it more [seriously]... But I think everybody does, I think schools need to; it's not a case of if, you know, oh... I think sometimes people just think, if somebody went to them and said, I'm struggling, I can't breathe; oh, have a puff of your inhaler and it's going to make it all right. (FA07)*

### 8.3.6 Knowledge and awareness

The majority of the participants had been living with a child who was diagnosed with asthma since early childhood. Despite this, they admitted to being unaware that asthma was a condition which could result in death. There was also a concern about the complacency of some healthcare providers when dealing with asthma and the advice which participants received.

#### 8.3.6.1 No one told us you could die from asthma

All of the participants had been affected by an asthma death, yet the majority of them had been unaware that an asthma attack could result in the death of a child. They could not recall a healthcare provider discussing it with them in a consultation or during a hospital admission. Participants were reportedly aware that asthma affected oxygen levels, but they had never considered that without oxygen circulating in the

body they would have a respiratory arrest, which would subsequently result in a cardiac arrest and death if left untreated. The lack of awareness was also shared by friends and family.

*You know, everyone knows that if you have an asthma attack you can end up in hospital, you can't breathe, but not many people know it can kill you. And they do need to know that. (FA01)*

*Because I did think how can an asthma attack leave you dead; I couldn't get it to that extent. I didn't realise an asthma attack could cause a cardiac arrest..... But it shouldn't have to take a death of somebody that you know...[to find out you could die of an attack] (FA02)*

*Her friends were absolutely, like the younger people, were absolutely gobsmacked that asthma could kill you. That was the one thing that was coming through with every single of her school friends, and her friends. Her friends, her social clubs, everybody, was, the thing everybody said was, I didn't know asthma could kill you. (FA03)*

For participants who were aware of asthma deaths, some of them had a preconceived idea that it would only affect adults or those who had severe asthma, rather than anyone who had an attack having the potential to deteriorate and die.

*I mean, we were young parents with a young child. I never knew. I mean, maybe we did hear but maybe it...you heard about it because it was an older person (FA04)*

*But, I thought asthma killed asthmatics severe, you know, people with severe asthma, and my children didn't fall into that category, you know, my children was just an asthmatic cough. (FA07)*

A participant who had experience of living with their children's food allergy and asthma, discussed knowing that anaphylaxis could result in death if untreated. This had been discussed with her children, however she felt the need to protect them from knowing that asthma could also result in death, if untreated.

*But it's weird, because we did speak to our children about allergies, and fatal attacks for allergies. But we, I think because allergies wasn't something they had to cope with every day, it was just something that they had to try and avoid... and [they knew] anaphylaxis, if it's not treated, can cause death. .... Whereas, with the asthma, it's something they had to cope with on a daily basis, it wouldn't probably go away. But it was something we kind of wanted to protect them from, as well. (FA03)*

### 8.3.6.2 Ability to self manage

Aspects of self management of asthma were discussed in the interviews, including recognition of trigger factors, adherence, using an asthma plan and parental opinion.

#### Trigger factors

All of the participants were able to identify trigger factors for symptoms and previous attacks, which included animal exposure, colds and change in the weather. A few of the participants discussed allergens, particularly cats and dogs, and despite knowing their child was allergic to these, they described varying levels of background exposure leading up to the fatal attacks.

*....and he was allergic to certain cat hair, but he knew, because we had...we used to have two cats..... He wanted this cat [a fluffy cat]..... And the only thing that ever affected him was if he fussed her too much and he was too close, if she moulting, the fur would get up his nose and it would make him sneeze and his eyes would go red, but it never actually affected his breathing. But once we'd figured that out, we knew for him not to...you know, like spend loads of time with it sat on his knee or... You know, we sort of limited his exposure to her, but we didn't get rid of her. ... and he was like, I like my cat. But luckily, like I say, it was just exposure...too much exposure..... (FA01)*

*[she was allergic to] dogs and cats, she was allergic to, and horses. She had, she loved animals, completely loved animals, and she would rather have an allergic reaction, than not stroke a cat, or stroke a horse, or whatever. So, she kind of put asthma second, and her life first. [family had a cat] (FA03)*

*[child with family friend at time of onset of fatal attack]. But then she had a dog because that could trigger him sometimes, so I don't know. Some dogs, but he knew what dogs he could be near and knew what ones he had to keep his distance from. (FA04)*

Some of the older children had tried smoking in the past or were regular smokers of tobacco or cannabis. Although a few of the parents smoked, they did this outside, as they recognised it as a possible trigger factor for asthma symptoms.

*But I do believe that she [smoked]...and she did admit to it, but she did then admit to the fact that she wasn't any longer. I never, there was never any cigarettes lying about. So I don't know if it was maybe, she smoked,*

*if someone was smoking, she would maybe take a wee smoke from them, or whatever. (FA03)*

*He didn't smoke a lot as in a normal cigarette, he did always tell me that he had smoked cannabis; and maybe that got worse, I'm not sure if there was anything else, there probably was, that he'd taken, which probably didn't help. (FA02)*

## **Adherence**

Taking medications on a daily basis was a matter of routine for many of the participant's children as there was an understanding that it would control their asthma and prevent attacks.

*She would never miss an inhaler, or she had a tablet as well that she took, she would never miss that. And she was quite regimented at taking her inhalers, yeah, and I didn't have to remind her, it was just something that, obviously when she was older, it was something that she just did all the time. And she was quite confident about it. (FA03)*

As the children got older, there was a shift in responsibility for taking medication. In the primary school years, parents tended to administer the medication, however, the young people and young adults had responsibility for this. The young adults still relied on their parents to order medication for them.

*He didn't take his preventer properly, if at all, certainly as he got older. There's so many upstairs in the drawer that's still in the packaging, never touched. And I don't think he saw the severity that he needed to take it; I think (name) used to think, oh, the reliever will do the trick; and he didn't, to be honest, always take that properly. And definitely he never took the...he hadn't took the preventer properly for a long time, he just thought the reliever was the only thing that did the trick. .... Because (name) would just text me and say, Mum, can you get my inhalers, I've run out, you know; and I used to think, well, you can get here, there and everywhere to go and meet your friends, but he couldn't get himself to the doctor's; well, I can't speak to anybody, you'll have to do it.(FA02)*

## **Asthma plan**

Many of the participant's spoke of having an asthma plan in place, which helped them identify warning signs and make decisions about treatment. Asthma plan provision appeared to be variable, with some not receiving plans until after they experienced a severe attack requiring hospitalisation.



*... the asthma plan was just step by step, what to do, when she felt her asthma was getting worse, to increase the inhalers. Or just talking her through, going up to hospital admission, if needed. (FA03)*

*I didn't get a management plan, what to do in her...until she...her near fatal one. Well before her last fatal one, and that was 'cause (place) put it in and that was when they put the oxygen in for her, 'cause I had to go home with nebulisers. (FA07)*

A few of the mothers discussed how they felt they were able to recognise and treat their child's asthma symptoms, as opposed to the father of the child. This may be related to parental work schedules, families living apart, or awareness of asthma and how to manage it.

*If I wasn't here or if I was at work, I could sometimes come home, and she'd be sitting on the couch, and she maybe wouldn't have said to my husband [having asthma symptoms] who didn't pick it up as much as I did. And I hate saying that, but... ..I kind of tapped into it more, probably because I was more with them (FA03)*

*I think I'd gone to pick him up from his dad's one night, and when I got there he was in the...he was in the midst of what everyone thought was an asthma attack, and they were all flapping and they didn't know what to do. I was like, have you given him his inhaler? Oh, well, he was only playing football and he's fine. I was like, well, no, he's not fine now. .... And he just looked... And you could see the look in his eyes, as if to say, thank god you're here. (FA01)*

### **Healthcare professionals knowledge**

All of the participants talked about the asthma care their child had received either in the GP surgery, or in hospital. Conversations with the participants regarding healthcare professionals focused on asthma education, management of recurrent attacks and diagnosis. These areas all provided opportunities to make changes or provide further information to empower parents to manage their child's asthma more effectively.

*A lot of the doctors are quite happy to give them the inhalers, and, you know, like tell them about asthma, but they don't necessarily show them how to use the inhalers properly. .... because if they're not using their inhalers properly, they're not getting their medication properly, which means they're going to be going back to the doctor's or back to hospital,*

*because they're not getting the medication, which, in turn, is not managing the asthma. (FA01)*

*On looking back on it, the only thing that does, that I feel might have gone better is, in the last year, or year and a half, I think she was in hospital about five times. And I just feel, I wish I, or the hospital, had said, look, this isn't right, we need, there's something going on here, we need to get to the bottom of this, this is happening too much now. Erm, I don't know if that would have changed anything (FA03)*

*That is what I want to get out there, so that is what I want to tell people, look this is what...how my daughter died, so don't think that an asthma attack had to be that wheezing, because it's not, so that's where I get very frustrated when people say, oh there's not a wheeze, it's not asthma because there's not a wheeze. You know, and I want to tell people that if you can see somebody presenting with these symptoms, if they have got a persistent cough, then push for, you know...because maybe had (name) have been prescribed steroids at some point, then maybe it would have had a different outcome. (FA05)*

### **8.3.7 Impact of previous attacks**

All of the participants had experience of their child having an asthma attack in the past.

#### **8.3.7.1 Asthma attacks v panic attack**

Having an asthma attack will cause a level of anxiety, and a few of the participants described previous asthma attacks, but also mentioned panic or panic attacks. There is potential to misinterpret an asthma attack for a panic attack and not treat it accordingly.

*.... she was back in work and she was struggling. But, she used to ring me and say, I'm so tired walking down the stairs mum, but we thought maybe she was just getting a bit panicky, 'cause she'd been seen by the doctors so many times. And, so we just thought, maybe, she was just getting, like, a little bit like panic attacks (FA05)*

*He had a minor chest infection and it was more a panic attack that he'd had rather than the asthma attack. And they said that he was probably developing the symptoms of an asthma attack, and because nobody knew what to do, it's panicked him and made him hyperventilate rather than have the asthma attack, if that makes sense....He just couldn't breathe but he looked okay (FA01)*

*And he's woke me a few times in the night to say, I'm struggling, I can't breathe. And I think he felt a bit comforted if somebody was sitting there with him to help him, because he used to panic, and I don't think that*

*helped as well that he couldn't breathe, and he'd be panicking about it.*  
(FA02)

#### **8.3.7.2 Previous management of an attack**

As all of the participants had experience of previous asthma attacks they discussed how they compared previous attacks to the current attack, when deciding how to treat it, or get medical attention.

*He'd had an asthma attack once and his oxygen levels were down to 64 per cent, he was blue, and we were... I think were waiting about 20 minutes for an ambulance at that point. So you know when you think... When I think back to his previous asthma attacks and how bad they appeared, I was quite calm, because I thought, oh, he's fine, he looks alright and he's just panicking. And then it just all went wrong, and I thought, well, this hasn't happened before [respiratory arrest].* (FA01)

As some of the children got older, they were more reluctant to go to hospital and there was a potential that they would under report symptoms to their parents. Any delay in receiving medical attention could affect outcomes of an attack.

*Yeah, I think, she didn't want to be admitted to hospital, and she knew that if she went to hospital, she would be admitted, because her history of asthma. And I think she just played it down. And she wasn't very happy about it, 'cause she didn't want to be taken into hospital. The paramedic arrived before the ambulance, and she said to me, if the paramedic gets me sorted, like he always does, can you can cancel the ambulance, and I said, I looked at the paramedic, and he gave me a look like, no. And I said to her, right, well we'll see, we'll see how the paramedic, how it goes. [minutes before she had a respiratory arrest]* (FA03)

Previous asthma attacks were identified as the greatest risk factor for future attacks in children. All of the participants' children had experienced a previous attack however some had experienced an attack within a week of their death. Although the typical length of steroids is three days for children and young people, a more prolonged course for complete resolution of symptoms, may be required if the child remains symptomatic after three days.

*They always give her [prednisolone]...they normally...it was either three days' worth or sometimes five, it depends really how...what they thought.*

*She went into hospital, she was home about a week. And then she was back in again. Then she got home and died two days later (FA07)*

*[the week before] So we had the hospital, we had the dentist, then her asthma did flare up a bit. And we went to the doctor's, and the doctor gave her prednisolone. And the course of prednisolone had finished, and she seemed to be back on track again. (FA03)*

A few of the participants had other children with asthma. Knowing their sibling had died of an attack had an impact on their sense of mortality. Awareness of this would be important for the ongoing management and support of children who had been affected by asthma deaths.

*And it's not like an illness that'll get better, it's just something that we're gonna have to cope with all our lives. And it makes it doubly as hard, because I've got a son that has asthma. And he fears that, because it happened to his sister, it could happen to him. (FA03)*

*Because his big brother died of asthma at eight (name) grew up till he was eight thinking he was going to die when he was eight. And it was a huge relief when (name) hit eight because we were like, oh, we've made it which sounds really, really stupid. And I remember saying to the hospital asthma nurse in clinic one day the relief that he got to eight, it was just huge. And I think it's a shame we've had to lose (name) but I think a lot of people have learned from this experience. (FA04)*

*One day I am going to die of asthma like [sibling] (FA07)*

## **8.4 Conclusion**

In this chapter, I have presented findings from the seven semi-structured interviews undertaken with parents exploring their perspective of a fatal asthma attack. The themes identified as key time critical events around the time of the event, which included the power of intuition and use of emergency medication, may offer clinicians some topics to consider from the perspective of parents affected by asthma deaths. The behaviours and circumstances which were identified may offer clinicians some insight into a number of factors which affect parents and children on a daily basis but most importantly we need to ensure that parents and patients are aware that some asthma attacks can result in death. These behaviours and circumstances will be discussed in chapter nine and will address the fourth aim of the study.

## **8.5 Summary and next steps**

In this chapter, I have presented findings from the seven semi structured interviews undertaken with parents exploring their perspective of a fatal asthma attack in response to the first three aims of the qualitative study. In the following chapter I will discuss the findings of both the near fatal and fatal interviews in further depth.

## **9 Chapter Nine: Discussion**

### **9.1 Introduction**

In this chapter I will summarise the principal findings from the qualitative studies in relation to the PhD aims, discuss the key findings in relation to published literature and theory, and highlight the strengths and limitations of the thesis.

The qualitative component of this thesis aimed to explore parent and patient perspectives of fatal and near fatal asthma. The aims set out at the start of this thesis were as follows:

- Identify key time-critical experiences of those who have experienced NFA (or their parents) that may provide a window of opportunity to seek help
- Understand family circumstances and behaviours that may place children and young people at greater risk of asthma death/near fatal asthma
- Understand the long-term psychosocial consequences of NFA
- Use these findings to inform key stakeholders such as education, primary care, severe asthma registries and emergency service responses in order to reduce the risks of fatal and near-fatal asthma and provide appropriate support for CYP, young adults and their families

### **9.2 Summary of findings**

There were a number of themes and subthemes created following analysis of the data. With regard to the first aim, key time-critical experiences, parents and young adults provided insight into how they managed asthma attacks at home and when they perceived medical attention was required. This experience was related to either a NFA attack or fatal attack. However, we also discussed management of other asthma attacks. The themes relating to this were: the power of intuition and emergency management. Parents and young adults further described behaviours and circumstances that addressed the second aim, around asthma management and

family dynamics, which highlighted potential opportunities to modify practice or provide education to prevent future attacks and asthma deaths. The themes relating to this were: knowledge and awareness and the impact of previous attacks. Aim three was to explore the long-term psychosocial impact of a NFA attack and this was addressed considering the psychological and social impact of attacks on the whole family. I will now consider the themes and how they relate to the supporting literature and address aim four, with suggestions on how to inform key stakeholders about these findings. I will also refer to the socio-ecological model which was introduced in section 2.12.2. and explain how each of the themes fit within it.

### **9.3 Key time critical experiences**

Key time critical experiences refer to a stage(s) in an attack which may offer a window of opportunity to get medical help to prevent deterioration or subsequent death during a severe asthma attack. The main overarching themes found in both studies were: the power of intuition and emergency management.

#### **9.3.1 Power of intuition**

'Gut instinct' or parental/ personal intuition was a recurrent topic of discussion in the majority of interviews. Parents or young adults stated that they had a feeling that they needed to get urgent medical attention for their child/ themselves.

Intuition, as a style of information processing, involves implicit perceptual and cognitive processes which automatically occur without conscious mental will, such that people know more than they can describe (Buetow and Mintoft, 2011). Parental intuition is generally based on their knowledge and emotional attachment to their child (Birchley, 2015). Overtime, parents become an expert of their own child, sensing change and situations when they need to get help however it can sometimes be difficult to articulate the exact reason for concern. Parents in my study described subtle changes such as, 'not looking right' or 'having a feeling something wasn't right',

which made them keep a more watchful eye. Buetow and Mintoft discuss the scenario of a child waking through the night with a wheezy chest (Buetow and Mintoft, 2011). This had happened in the past, however on this occasion, the parent feels especially apprehensive for no tangible reason which could be articulated. However, this prompted the parent to seek medical review, albeit it with some uncertainty, as they were aware of the potential harm that could result if not acted upon. In my study, one of the parents of a child who had a NFA attack described how in the past she attended the Emergency Department (ED) and explained to a junior doctor that her son was not well and she just knew something was different. She felt her opinion was not taken seriously and discharge was planned until a senior ED consultant reviewed the child and recognised her son was having a severe attack with a silent chest. The parent discussed how this experience helped reinforce that her intuition was credible. In clinical practice, it would be important to reflect on previous attacks with parents and help them tease out if they had a gut feelings in relation to the event. Adding a prompt of, “you may get a feeling that something isn’t right but is hard to explain – don’t ignore it” into an asthma action plan may empower parents/ patients to act upon these feelings at the appropriate time. It could also help clinicians view this as an important part of the assessment process when reviewing a child who is experiencing an asthma attack.

### **9.3.2 Emergency management**

Participants in my study (both parents and young adults) discussed their asthma plan which included the use of multi dose salbutamol (10 puffs x 100 micrograms salbutamol) for an asthma attack. There was a difference in opinion of when they should have a medical review, with some closely following a plan of 2 multi doses and others as many as ten multi doses. Despite the differences, each of the participants



perceived their interpretation of the management plan was created in agreement with a clinician.

The management of acute asthma in children underwent a significant change in practice in the early 2000's, following the publication of a paper by Powell et al., and a subsequent systematic review by Cates on the use of spacers versus nebulisers for the treatment of a mild to moderate asthma attack (Cates, 2003, Powell et al., 2001). This systematic review has undergone several iterations however continues to support the findings of a reduction in length of stay in the ED and a lower heart rate in children if spacers are used in preference to a nebuliser to deliver bronchodilator (Cates et al., 2013). In the studies, ten puffs of salbutamol was compared to a nebuliser, which is why the ten puffs of salbutamol has become ingrained in practice. The action plan available via Asthma UK (Figure 33) advises the use of up to ten puffs of salbutamol for an asthma attack and a medical review on the same day to prevent further deterioration. Provision of the plan is only one step in the process of self-management, and should be done in conjunction with education forming a self-management strategy (Pinnock, 2015).

**Figure 33: Child's asthma plan available from [www.asthma.org.uk/advice/child/manage/action-plan](http://www.asthma.org.uk/advice/child/manage/action-plan).**

**My Asthma Plan**

**1 My usual asthma medicines**

- I need to take my preventer inhaler every day. It is called \_\_\_\_\_ and its colour is \_\_\_\_\_
- I take \_\_\_\_\_ puff/s of my preventer inhaler in the morning and \_\_\_\_\_ puff/s at night. I do this every day even if my asthma's OK.
- Other asthma medicines I take every day: \_\_\_\_\_
- My reliever inhaler helps when I have symptoms. It is called \_\_\_\_\_ and its colour is \_\_\_\_\_
- I take \_\_\_\_\_ puff/s of my reliever inhaler when I wheeze or cough, my chest hurts or it's hard to breathe.
- My best peak flow is \_\_\_\_\_

**2 My asthma is getting worse if...**

- I wheeze or cough, my chest hurts or it's hard to breathe **or**
- I need my reliever inhaler (usually blue) three or more times a week **or**
- My peak flow is less than \_\_\_\_\_ **or**
- I'm waking up at night because of my asthma (this is an important sign and I will book a next day appointment)

**If my asthma gets worse, I will:**

- Take my preventer medicines as normal
- And also take \_\_\_\_\_ puff/s of my blue reliever inhaler every four hours
- See my doctor or nurse within 24 hours if I don't feel better

**URGENT!** If your blue reliever inhaler isn't lasting four hours you need to take emergency action now (see section 3)

**Other things to do if my asthma is getting worse**

Remember to use my spacer with my inhaler if I have one. (If I don't have one, I'll check with my doctor or nurse if it would help me)

**3 I'm having an asthma attack if...**

- My reliever inhaler isn't helping or I need it more than every four hours **or**
- I can't talk, walk or eat easily **or**
- I'm finding it hard to breathe **or**
- I'm coughing or wheezing a lot or my chest is tight/hurts **or**
- My peak flow is less than \_\_\_\_\_

**If I have an asthma attack, I will:**

- Call for help**
- Sit up** — don't lie down. Try to be calm. Take one puff of my reliever inhaler (with my spacer if I have it) **every 30 to 60 seconds** up to a total of 10 puffs.
- If I don't have my blue inhaler, or it's not helping, I need to call 999 straightaway.**
- While I wait for an ambulance I can use my blue reliever again, every 30 to 60 seconds (up to 10 puffs) if I need to.

**Even if I start to feel better, I don't want this to happen again, so I need to see my doctor or asthma nurse today.**

The overuse and over prescribing of salbutamol ( $\geq 3$  SABA canisters<sup>11</sup> in 12 months) in children has been identified as a risk factor for future attacks, hospital admission and asthma deaths (Hull et al., 2016, Nwaru et al., 2020). Following the change in practice in the management of asthma attacks with inhaler and spacers, a wheeze discharge plan was implemented by individual health boards and Trusts, providing guidance on weaning the use of salbutamol via the spacer, in the recovery phase of an attack. There are currently no clinical trials or evidence based guidelines on this practice which has resulted in wide variation throughout the UK (Yianni et al., 2016). There was an interesting debate amongst leading physicians in the UK following the publication of Keely and Baxter's article on conflicting asthma guidelines in primary care (BTS/SIGN versus NICE), with divided opinion on the use of a salbutamol

<sup>11</sup> Short Acting Beta Agonist (SABA) refers to both salbutamol and terbutaline. Terbutaline is available as a dry powder device and not compatible with a spacer. All participants in my study used salbutamol.

weaning plan in children after discharge from hospital (Keeley and Baxter, 2018) . This debate is published in the response section of the article online. Dr Levy (London), supported by members of the GINA science committee, wrote in response to this article expressing concerns about the unlicensed use of multi dose salbutamol four to six hourly on discharge, which often extended over a number of days. They argued that this placed children at risk of undetected and possibly life-threatening deterioration. Dr Paton (Glasgow) and colleagues disagreed, stating this practice facilitates early discharge and provides patients with a strategy to manage future attacks. Such a strategy gives permissive clinical permission for parents to provide frequent and high dose SABA during an acute attack. The discussion concludes with a call for research to establish the safety, cost effectiveness and clinical outcome of the use of weaning plans involving regular administration of salbutamol. This discussion is reflective of how practice differs within the UK, leading to confusion for parents and children who may be cared for in more than one hospital or NHS trust. Rather than using the term 'multi dose' adoption of either the terms, 'emergency dose' or 'rescue dose' could be considered, which may make individuals think about why they require multiple emergency or rescue doses, thus prompting medical review. It is worthwhile noting that children may always over order salbutamol due to lifestyle, rather than overuse. Children require salbutamol inhalers for home use, school use and often chose to have a salbutamol inhaler at a relative's house. Children often misplace inhalers and will need to reorder. Documentation from the prescriber, with the rationale for prescribing numerous salbutamol inhalers, may help to address this issue.

As an alternative approach to managing asthma symptoms/ attacks, GINA recommend that mild asthma in adolescents (and adults) could be treated using a combination ICS-formoterol only (Reddel et al., 2021). Clinical trials, in children  $\geq 12$  years, have shown that using 'as required' combination ICS-formoterol, reduces

severe attacks by  $\geq 60\%$  in mild asthma compared with SABA alone, with similar outcomes as daily ICS plus as required SABA (Sobieraj et al., 2018). This treatment can also be used for moderate to severe asthma as Maintenance and Reliever Therapy (MART), with daily dosing to prevent symptoms and also to relieve symptoms. This approach is currently supported in the NICE Guideline on Chronic Asthma Management (NICE, 2021). The current British Guideline on the Management of Asthma does not include MART approach, however this may change with the amalgamation of this guideline with the NICE guideline, which is expected in November 2023 (BTS/SIGN, 2019). Starting treatment with SABA only treatment (as per the current NICE guidelines) “trains” the patient to regard SABA as the mainstay of asthma therapy, potentially leading to over-reliance, whereas starting with ICS-formoterol avoids this risk. Furthermore, using ICS-formoterol as a reliever inhaler at all treatment steps, avoids the risks of patients using SABA only treatment, if adherence to maintenance preventer treatment is poor. This approach will require a joint approach from clinicians and patients to consider a strategy in changing behaviour, and lessons could be learned from European colleagues, who may have implemented this change according to the GINA strategy (GINA, 2021).

Children in the recovery phase of an attack, either at home or in hospital, can still be at risk of sudden deterioration, and it would be important to include this information when discharging a patient from hospital, or when a patient has been prescribed oral steroids for an attack in primary care, or the ED. One of the participants in the NFA attack study, discussed how her daughter was due for discharge in the morning as she was stable on four hourly multi dosing. She experienced a respiratory arrest on the ward in the early hours of the morning. The emergency zone of the asthma plan should be devised in partnership with the child and family and provided in a format which can be understood either as a written, audio or infographic plan, to address literacy and language barrier (Miles et al., 2017, Lakhanpaul et al., 2017). With the

recent surge in patients purchasing pulse oximeters (measure oxygen saturation levels) for home use due to the global covid 19 pandemic, there could be a role for these oximeters to be used as part of an asthma plan. This would need a cautious approach due to the recent patient safety alert, produced by NHS Improvement, that highlighted if an oximeter probe intended for an adult is attached to a baby or a child (or vice versa), it can produce a reading up to 50% lower or 30% higher than the real value (NHS Improvement, 2018). A recent Cochrane review was conducted to determine whether pulse oximeters used as part of a personalised asthma action plan for people with asthma are safer and more effective than a personalised asthma action plan alone (Welsh & Carr, 2015). They found no reliable data to support or contest patient use of pulse oximeters to monitor oxygen saturation levels when experiencing an asthma attack. The use of home oximeters may at this stage be more appropriate for teenagers and adults and used in accordance with agreed parameters recorded within an asthma plan and made in agreement with a healthcare professional. It would also be important to address the role hypoxaemia plays in making decisions (see section 9.4.2).

## **9.4 Behaviours and circumstances**

Participants in all studies offered insight into personal behaviours and circumstances that may have had an impact on the outcome of their/their child's asthma attack. The main overarching themes relating to behaviours and circumstances were: knowledge and awareness; the impact of previous attacks; the psychological impact of attacks.

### **9.4.1 Knowledge and awareness**

This theme related to participants personal knowledge and awareness of asthma. Education in relation to asthma deaths was not routinely provided. Participants also spoke about clinicians and how they perceived those providing clinical care were not always consistent in either their management of an attack or advice provided.

#### **9.4.1.1 Talking about asthma deaths**

Living with asthma for as long as they could remember, the young adults participants perceived having asthma as their normal. They had not adapted their lifestyle around asthma, rather incorporated it into their lifestyle. They could recall receiving some asthma education in the past, but were not all aware that asthma attacks could result in death. Similarly, some of the parent participants were not aware that asthma attacks could kill and if they had heard of asthma deaths, they perceived these to occur in adults rather than children. Talking about the risk of death is important. In conditions such as epilepsy (Sudden Unexpected Death in Epilepsy) and severe allergy (anaphylaxis), discussing the risk of death has become the norm however in asthma care it appears to be less frequently discussed. There is no clear rationale why the risk of asthma death is not discussed in an asthma review, or at the time of diagnosis. This could be attributed to a concern that discussing death may cause anxiety in a child with asthma, which might trigger attacks. In contrast however, the risk of death in children with food allergy seems to drive “positive” patient behaviours, such as avoiding certain foods. This gap in knowledge highlights research need.

#### **Lessons learned from epilepsy**

According to Epilepsy Action (2021), the incidence of SUDEP in the UK is similar to the number of asthma deaths that occur on a daily basis in the UK, with 21 people dying per week. The incidence of SUDEP is greater in adults, with 1:1000 compared to 1:4500 in children. Shankar et al. have developed a discussion pathway for neurologists (Figure 34) to discuss SUDEP for those recently diagnosed with epilepsy (Shankar et al., 2017). This pathway provides guidance on how to start the consultation and who should be involved. The person’s knowledge on adverse outcomes in epilepsy are explored, SUDEP is explained, and then put into context. Patients are then provided with time to reflect on what they have learned and signposted to reliable online resources for further information. Importantly, all this

information is documented to aid future discussion, but this could be taken a step further, with a copy of the discussion being sent to the patient and their family in order to reflect upon it, in the future or to share with members of the extended family.

**Figure 34: Suggested SUDEP discussion pathway for a recently diagnosed patient with epilepsy.**  
(Shankar et al., 2017)

|                                                                                                                                                                                                                                                                                                      |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Include in an early appointment, with a clinician or specialist nurse, an offer to discuss the recent diagnosis of epilepsy and its implications. Invite the patient to bring along a family member or friend.                                                                                    |
| 2. Ensure the patient is comfortable and give enough time for questions and discussion.                                                                                                                                                                                                              |
| 3. Explore the understanding of the diagnosis of epilepsy and its particular relevance to them. Establish what they know about possible risk issues arising from epilepsy.                                                                                                                           |
| 4. If a relative or friend witnessed the person's seizure, ask what their thoughts were.                                                                                                                                                                                                             |
| 5. Enquire sensitively if the patient is familiar with any direct adverse outcomes of epilepsy.                                                                                                                                                                                                      |
| 6. Ask if they have come across the term SUDEP (Sudden Unexpected Death in Epilepsy).                                                                                                                                                                                                                |
| 7. Enquire if they would be interested in knowing more.                                                                                                                                                                                                                                              |
| 8. Explain the entity including that this is usually related to the after-effects of a severe seizure, putting a strain on breathing and heart function.                                                                                                                                             |
| 9. Offer reassurance that it is a rare event which perhaps occurs in the range of 1/10,000 person-years among new-onset cases, though the risk can be considerably higher; 1/1,000 in chronic epilepsy, and even higher in poorly controlled epilepsy with ongoing convulsions.                      |
| 10. Put this risk in context of other risks we take in our daily lives.                                                                                                                                                                                                                              |
| 11. Cover core risk factors listed in <i>table 1</i> , systematically allowing the patient/carer or companion to clarify any item.                                                                                                                                                                   |
| 12. Highlight other indirect factors which could impact on seizure control ( <i>table 1</i> ), tailoring the discussion to the individual patient.                                                                                                                                                   |
| 13. Ask the patient and/or carer to reflect on what they have learnt from the consultation including, where appropriate, positive measures to minimise his/her risk.                                                                                                                                 |
| 14. Encourage reflecting and planning on how the PWE will recognise a change in individual risk and what action to take.                                                                                                                                                                             |
| 15. Provide relevant information or sources: <a href="http://www.sudep.org">www.sudep.org</a> ; <a href="http://sudepaware.org">sudepaware.org</a> ; <a href="http://www.epilepsy.com">www.epilepsy.com</a> ; <a href="http://www.sudepglobalconversation.com">www.sudepglobalconversation.com</a> . |
| 16. Record the discussion including the PWE's attitude towards self-management of risk with a view to informing future discussions.                                                                                                                                                                  |
| 17. Re-visit risk factors briefly in future appointments and consider using tools such as the SUDEP and seizure safety checklist ( <a href="https://www.sudep.org/checklist">https://www.sudep.org/checklist</a> ).                                                                                  |

## Lessons learned from anaphylaxis

The incidence of death due to anaphylaxis is much lower than asthma, with approximately 20 deaths per year. Patients deemed to be at increased risk of death (e.g. previous anaphylaxis or asthma and co-existing food allergy) are provided with potentially lifesaving adrenaline auto injectors, supported with instruction on use and education on how to minimise personal risk (Ewan et al., 2016) .

The risk of asthma deaths needs to be openly discussed and not remain a taboo subject for fear of causing upset. This could be approached as an open question, “what do you think is the worst thing that could happen if you/ your child had an asthma attack?” Participants in this study reported feeling that it was better to cause some initial concern or upset to a parent, than not to discuss it and leave them in ignorance, and potentially losing their child as a result of an attack. Another important finding from the asthma deaths study was the perception of siblings, who also had asthma, perceiving they would die of an asthma attack in the future. One of the participants discussed how her son was relieved on his 8<sup>th</sup> birthday to be alive, as his brother had died just before his. Another participant discussed how her son told her he thought he would die in the future. Awareness of this concern could be raised in future asthma reviews, and support mechanisms, such as referral to a psychologist, could be put in place. There would be scope for exploring this in more detail in the future, as it currently appears to be anecdotal. Raising the profile of asthma deaths in the wider community could also help combat the ‘it’s just asthma’ attitude.

#### **9.4.1.2 Clinician’s knowledge**

Some of the adult participants in both the fatal and near-fatal study, felt their hospital based doctor lacked knowledge in managing a severe asthma attack or routine care. One of the young adults explained how she thought she would die in the future as a result of the care she received in hospital, as she stated the clinical staff were not acknowledging/ recognising how severe her attack was despite both her mum and her asking to be reviewed. Clinicians involved in providing asthma care need to have a level of knowledge and skills in relation to the level of care they are providing to patients however there is no current requirement in the UK to evidence this (Levy et al., 2014). Within the UK, asthma care is guideline driven and relies on clinicians keeping updated and locally adapting guidance. Adherence to national asthma



guidelines leads to health improvements and better quality of life of asthma patients (Ahmad and Sorenson, 2016). Ahmad and Sorenson further demonstrate that following guidelines leads to decreased asthma-related hospitalisation and emergency care use. From the findings of their systematic review, they report lack of awareness, lack of familiarity, lack of agreement, lack of self-efficacy, lack of outcome expectancy, inertia of previous practice and time limitations as reasons why guidelines are not followed.

In addition to following guidelines, clinicians need to be able to interpret guidance and have the clinical skills to apply guidance into practice. Clinical reasoning is a perennial focus of medical education, performance assessment, and study (Gruppen, 2017). There is no generally accepted definition of what clinical reasoning is. Gruppen proposes clinical reasoning includes the integration of the physician's knowledge with patient information to form a case representation of the problem. This then starts a cycle of requesting more patient information, until a threshold of confidence is reached to support either a final diagnosis or management plan. Developing clinical reasoning skills in asthma care can be aided by the application of a learning model.

Applying the conscious competence model may be an appropriate place to start (Cutrer et al., 2013). This model moves through four progressive stages with an option of a fifth, as presented in Table 53.

**Table 53: The five stages of the conscious competence model.**

(Adapted from Cutrer et al., 2013)

| Stage                        | Explanation of stage                                                                                                                               |
|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 – Unconscious incompetence | Learners are unaware of what they do not know and are often very eager to learn                                                                    |
| 2 – Conscious incompetence   | Where a learner becomes aware of his or her limited knowledge                                                                                      |
| 3 – Conscious competence     | The learner has gained significant skill and functions well clinically, but each step requires deliberate thought and action                       |
| 4 – Unconscious competence   | The learner functions more instinctively with less deliberate attention, switching to an analytical mode only when necessary.                      |
| 5 – Reflective competence    | Offers one potential mechanism to avoid the slip backwards to unconscious incompetence as well as to maintain the consciousness of clinical skills |

A participant in the fatal study explained how her child's care was provided at their local District General Hospital (DGH). Despite her child experiencing frequent attacks requiring hospital admission and the parent's request for referral to a larger centre, no action was taken until her daughter had a NFA attack. She explained that the doctor in the DGH told her there was nothing the other hospital could offer other than oral steroids. This would be an example of unconscious incompetence. In section 9.4.2.2, a parent participant provided her account of a junior doctor assessing her child and planning discharge, as he did not have any wheeze heard on auscultation. When the parent challenged this decision, her child was reviewed by the consultant and found to have a silent chest. This would be an example of unconscious incompetence in the junior doctor and unconscious competence in the consultant. Awareness of asthma guidelines and acceptance of personal limitations should improve care provided and prompt referral/discussion with other colleagues, if a patient appears to have asthma which is difficult to treat or control.

In 2021, NHS England, NHS Improvement, commissioned a body of work - The Children and Young People's (CYP) Transformation Programme (NHS England, 2021). This programme aims to develop a National Bundle of Care for Children and Young People with Asthma that covers: environmental impacts; accurate and early diagnosis; effective preventative medicine; managing exacerbations and severe asthma.

Two additional working groups have been formed to support the development of the bundle: asthma competencies training and education needs; and data & digital. The term competency has subsequently been replaced with capability, as there was a debate regarding who was qualified to deem someone competent. Through engagement with professional bodies and Royal Colleges to align the capabilities with other established frameworks, a 5-level tiered framework has been developed for anyone involved in the care of CYP with asthma. Suggested professionals for each tier, ranges from teachers and after school clubs in tier one, to tertiary centre consultants and members of a difficult asthma multidisciplinary team in tier five. The capabilities will be launched in England in spring 2022 and will take time to become embedded into clinical practice. It is difficult to predict what outcome these capabilities will have in improving patient care and reducing risk of attacks and asthma deaths, however this is a positive first step to standardise knowledge and skills of those providing asthma care in England.

#### **9.4.2 Impact of previous attacks**

With the exception of one parent participant in the fatal study, all other participants in both the fatal and near fatal studies had previous experience of an asthma attacks which resulted in hospital admission. In a recent systematic review by Buelo et al. previous asthma attacks were recognised as the greatest risk factor for future attacks in children aged between five and 12 years, with persistent symptoms recognised as a moderate risk factor (Buelo et al., 2018). Participants in my study discussed

frequent asthma attacks and admissions as if they were the norm and were unaware of the heightened risk of future attacks. It is difficult to establish if participants simply got used to accepting asthma symptoms as normal, thereby establishing a new threshold for seeking medical review, or if they became more subconsciously tolerant of symptoms. Julius et al. reported the presence of a subpopulation of patients, who had experienced life threatening asthma, had a reduced perceptual sensitivity to inspiratory loads (Julius et al., 2002). This led to poor perception of severity of bronchospasm and delay in seeking medical review. Patients, especially those who have experienced previous NFA attack, may benefit from using objective measures such as peak flow or home spirometry on a regularly basis to help identify subtle changes in their status to them. This would require adherence, with monitoring, in addition to the existing challenge of adherence to medication. Some of the young adult participants described a reluctance to come to hospital due to previous experience, which could place them at greater risk of an adverse outcome. Additionally, a number of the young adults talked about the impact an attack had on them physically and psychologically. However, potential decision making around attending hospital in this group may have been influenced by lowered oxygen level in the body (hypoxia) during an attack. There are no current studies considering patient decision making when hypoxaemia for any health condition, however this has been studied in relation to activities at depth or altitude. Activities such as underwater diving and high altitude recreational activities can result in mild hypoxaemia. Poor judgments and decisions during these activities can be fatal, and this impact is also recognised as a potential for poor decision making during an asthma attack (Pighin et al., 2012). Encouraging early presentation to have a medical assessment in an attack, may prevent hospital admission and the potential impact of hypoxaemia on safe decision making should be discussed at an asthma review.

### **9.4.3 Psychological impact of attacks**

Participants in my studies reported a psychological impact following the NFA attack or fatal attack. For those affected by asthma death, they had a grieving process to follow and could access bereavement support from a variety of sources which included their GP, or from charities such as Cruse, or Child Bereavement UK. Of interest, and discussed after the recording of an interview had finished, one of the parents told me how she contacted Cruse after her daughter's death. The person she spoke with, asked about her recent bereavement and the cause of her daughter's death. She explained it was as a result of an asthma attack and the person she spoke with responded by saying she was not aware asthma attacks could result in death. This subsequently excluded this charity as a resource for this parent. The psychological support for those who had either experienced or witnessed an NFA attack appears to have been variable. Some participants discussed how it was offered, but declined, as they did not feel it was necessary. Others said it would have been helpful if it had been offered. Some of the young adults discussed the impact the attack had on their parents and siblings, and how psychological support would have benefitted the entire family. Parents who witnessed this event could recount their story in fine detail, even up to ten years (maximum time for this study) after the event had occurred.

Past research and clinical experience by Kean et al. suggest that young people with asthma and their parents may be at risk of Post-traumatic stress (PTS) responses following an asthma-related event, particularly events that are life threatening (Kean et al., 2006). Traumatic experiences include not being able to breathe, medical procedures such as an emergency intubation, and parents believing their child may die. The severity of an attack has a correlation with the risk of developing a PTS reaction (Wamboldt et al., 1995). Symptoms of PTS can include anxiety, avoidance, and experiencing distressing or uncontrollable thoughts relating to the event.

Avoidance of the trigger (in this case asthma and acknowledging symptoms) is one of the coping strategies people with PTS use, however this can lead to failure to treat asthma symptoms or have an impact on adherence with preventative treatment. In contrast, a heightened sense of arousal and intrusive thoughts triggered by asthma symptoms, can lead to a dysregulated emotional response, which compromises their ability to make a judgment on asthma attack severity and when medical help is required (Kean et al., 2006). Chung and Wall proposed that there is also a risk of the person who experienced the traumatic event, finding it difficult identifying and expressing emotion (alexithymia) relating to that event. They may use this as a coping mechanism, which could increase risk of a future adverse event, especially in relation to an asthma attack (Chung and Wall, 2013). Kean et al., encourages clinicians to screen for possible PTS and to refer to appropriate psychological treatment which will provide parents and children with coping mechanisms when faced with triggers (Kean et al., 2006). In addition to the psychological impact which is experienced post NFA, it is important to note that pre-existing psychological disorders, such as depression, are risk factors for NFA and fatal attacks. It is therefore important to be able to recognise these behaviours within a child and/or family member (BTS/SIGN, 2019). Through discussion with colleagues in the UK it would appear that psychological services are under-resourced and in high demand. Improving access for children and families will require prioritisation for funding to meet this critical demand.

## **9.5 Influences on outcomes**

It is important to consider all the key findings from these studies, but remember that they do not stand in isolation. Circumstances may allow for a favourable outcome on one day, and an adverse outcome on another. An example of how the outcome of a young person's asthma attack can be influenced by potentially modifiable circumstances, or variables, out with the control of the family, are presented as

scenarios in text box six and seven. These scenarios could be utilised in future educational training events.

These scenarios are hypothetical and do not relate to any of the participants in the study.

### **9.5.1 Scenario One**

Scenario one highlights a positive outcome from an asthma attack in a young person. She was aware of her trigger factors and recognised signs of deteriorating asthma. The young person's mother was able to initiate emergency treatment but recognised home management was not working and she required emergency medical care. She recovered well with appropriate changes made to her medication and a post attack review was conducted. Ongoing follow up was secured.

#### **BOX 6: AN ASTHMA ATTACK IN A YOUNG PERSON WITH A POSITIVE OUTCOME.**

Paula is a 12 year old girl who has had asthma since early childhood. Her asthma triggers are colds, exercise and allergies. She has allergies to cats, pollen and house dust mites. When she was younger she had a few hospital admissions. After referral to the asthma clinic, her medication was optimised and her attacks were less frequent. She has an asthma plan in place. She has received some asthma education, although this was primarily provided to her mother. In the summer, on a day when the pollen count is high, Paula starts to experience cough and wheeze. She starts to follow her asthma plan and uses her blue inhaler regularly throughout the day. At night, her breathing becomes more difficult and she phones her mum from her bedroom. Her parents come through to check her. Paula is exhibiting all the warning signs of an asthma attack, as she is finding it hard to breathe, can only speak in phrases, was unable to walk through to her parent's room, and is coughing and wheezing. Her Mum administers 10 puffs of salbutamol through the spacer which initially works for about 30 minutes. She is now coughing and can now only speak in words. She looks pale. Mum calls 999

and tells them her daughter is having an asthma attack. Dad continues to administer the salbutamol inhaler. The initial responder arrives within ten minutes and assesses Paula. The attack is classified as severe as in addition to her symptoms her SpO<sub>2</sub> is 90% in room air. Treatment is commenced with nebulised salbutamol and ipratropium via oxygen. She is transferred to hospital where she is treated with oral steroids, supplementary oxygen overnight and salbutamol through the spacer. She recovers within 36 hours and is discharged home with a recommendation to continue with current asthma treatment but with the addition of a daily antihistamine. She has a post attack review with her Practice Nurse within a week. Hospital follow up is in place.

Scenario two discusses the same young person a few months later. The decision makers remain the same in her care. She had been experiencing a period of instability leading up to this attack, having had an admission and 2 further courses of oral steroids for subsequent asthma attacks (increased risk factor for a subsequent attack). She had a cold (first trigger) and was exposed to a kitten (second trigger). She had an empty salbutamol inhaler (over use of SABA) when mum came to check on her through the night ('gut instinct'). When the family called for an ambulance the severity of the attack was not conveyed to the call handler and there was a delay in the paramedic arriving at the family home (delay in receiving medical attention). She was urgently transferred to hospital and was gravely unwell on arrival.

**BOX 7: AN ASTHMA ATTACK IN A YOUNG PERSON WITH AN ADVERSE OUTCOME.**

Paula has had a further two asthma attacks, triggered by colds since her summer admission. These have been managed at home with courses of oral steroids from the GP and advice to use regular salbutamol through the spacer. In December, Paula develops another cold but feels well. She has a runny nose but does not feel



tight chested or wheezy, and is not coughing. She is invited to a friend's house for tea, who has a new kitten that Paula's mum had not been aware of. Paula is allergic to cats. Her mum picks her up at 8pm and is concerned that Paula is now wheezy. Paula uses her salbutamol inhaler through the spacer when she returns home and goes to bed. Paula's mum mentions to her dad that she is worried about her, and decides to set an alarm on her phone so she can check her overnight. At 2am Mum goes through to Paula's bedroom and finds her gasping for breath, she finds the salbutamol inhaler empty beside her bed and calls for Dad to get the spare inhaler. She administers 10 puffs of salbutamol and asks Dad to call 999. Dad provides details and tells them his daughter is having an asthma attack but the information provided does not convey the seriousness of the attack. The first responder, who coincidentally is the same person who responded in the summer, arrives after 20 minutes and assesses Paula. He is very concerned and immediately calls for assistance. Paula is gasping for breath, centrally cyanosed, and has an altered level of consciousness. On auscultation, she has a silent chest. Her SpO<sub>2</sub> is 85% in room air. The paramedic follows emergency protocols for life threatening asthma and, on arrival of the second paramedic crew, Paula is prepared for urgent transfer to the ED. On arrival at the ED she is unconscious and unable to maintain her own airway. She is ventilated and spends a week in intensive care. Her attack is classified as near fatal.

These scenarios are reflective of how the outcome of the same patient, with the same care givers, experiencing an asthma attack can differ, when circumstances which influence poor outcomes in an attack, all align.

## **9.6 Applying the Socio-ecological model**

This model can assist to enhance understanding of the individual, interpersonal, community, organisational and public policy factors which may reduce asthma attacks

and prevent asthma deaths (Nuss et al., 2016, Lakhanpaul et al., 2014, Zaeh, 2022). It is also apparent from the summary in table 54 how factors at one level influence factors at another level and how important implementing change across multiple levels of the model at the same time are required to improve outcomes for children and young people affected by asthma.

**TABLE 54 KEY FINDINGS FROM THE QUALITATIVE RESEARCH WITH PARENTS AND YOUNG ADULTS AS OUTLINED BY CONSTRUCTS OF THE SOCIO-ECOLOGICAL MODEL**

|                        | Individual                                                                                                                                                                                                        | Interpersonal                                                                                                                                                                                                                                                                        | Community                                                                                                                                                                                                                                                                                              | Organisational                                                                                                                                                                                                                                                                                         | Public Policy                                                                                                                                                  |
|------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| The power of intuition | Intuition should be discussed in consultations at an age appropriate level. Children and young people should be empowered to act upon their gut feelings. A section on intuition should be added to asthma plans. | Parents and carers are the experts of their own children. Intuition should be discussed in consultations and parents should be empowered to act upon their gut feelings.                                                                                                             | n/a                                                                                                                                                                                                                                                                                                    | Parents may present to their GP, unscheduled care service, paramedics or the emergency department as result of their intuition. Parental concern should be acknowledged, discussed and acted upon as clinically indicated.                                                                             | n/a                                                                                                                                                            |
| Emergency management   | Children and young people should have very clear guidance on the use of their reliever inhaler and their asthma plan should be regularly reinforced.                                                              | Parents should have very clear guidance on the use of their child's reliever inhaler and their asthma plan should be regularly reinforced. This guidance should be extended to any family member, carer or family friends who may be responsible for the care of a child with asthma | Children will attend a variety of different places such as school, after school clubs, sports clubs etc. Asthma attacks can occur at any time and the adults who are assuming responsibility for a child with asthma should have clear guidance on the use of salbutamol and when to get medical help. | The use of salbutamol should be regularly reviewed by clinicians to ensure safe limits are in place for prescribing and use. E.g. GP's, GP receptionists, Pharmacists, Practice Nurses, Hospital Specialists. Guidance needs to be provided in a format which is appropriate for the child and family. | Asthma guidelines in both the UK (BTS/SIGN/NICE) and Global guidelines (GINA) provide guidance on the use of salbutamol but also offer other strategies (MART) |

|                             | Individual                                                               | Interpersonal                                                                       | Community                                                                                            | Organisational                                                                                                                                                                                                   | Public Policy                                                                                                                                                                                                                                                                                                                    |
|-----------------------------|--------------------------------------------------------------------------|-------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Talking about asthma deaths | Children and young people need to be aware that asthma deaths can occur. | Parents need to be aware that asthma deaths can occur in children and young people. | Members of the community need to be aware that asthma deaths can occur in children and young people. | Clinician's need to discuss the risk of an asthma death occurring with parents, child and young people in a sensitive manner.<br>Lessons should be learned from other conditions such as epilepsy or anaphylaxis | Asthma guidelines (BTS/SIGN/NICE and GINA) should continue to outline the risk factors for asthma deaths.<br>New academic literature should be systematically appraised and used to inform practice in relation to asthma deaths e.g. Cochrane library                                                                           |
| Clinician's knowledge       | n/a                                                                      | n/a                                                                                 | n/a                                                                                                  | Clinicians providing asthma care should be trained at a level appropriate. Training should be accessible to everyone. All organisations need to provide appropriate funding and mentorship for clinicians.       | NHS boards across the UK need to prioritise asthma care and provide access to training and education.<br>Professional bodies such as the Primary Care Respiratory Society, Royal College Paediatrics and Child Health, Royal College of Nursing, Royal Pharmaceutical Society should endorse high quality educational resources. |

|                                 | Individual                                                                                                                                                                                                                                                                                                                                                                               | Interpersonal                                                                                                                                                                                                                                                                                                                                                                             | Community                                                                                                                                                                            | Organisational                                                                                                                                                                                                                                                                                                                                                               | Public Policy                                                                                                                                                                                                                                                                                                                                |
|---------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Impact of previous attacks      | <p>Children and young people should be aware of their increased risk of an asthma attack if they have had a previous attack. Sometimes an individual will lose perception of their asthma symptoms increasing the risk of attack.</p> <p>Children and young people should be informed that when oxygen levels fall (hypoxaemia) during an asthma attack decision making is affected.</p> | <p>Parents and carers need to be aware of the increased risk of a subsequent asthma attack when their child has had a recent attack. They should also be aware that as an attack progresses their child's oxygen level will start to fall (hypoxaemia) which will have an effect on decision making and they will need to assume full responsibility for their child's medical needs.</p> | <p>Environments such as school, after school clubs, sports clubs should be made aware of an individual's recent asthma attacks and to discuss any concerns with parents/ carers.</p> | <p>Clinician's working in both primary and secondary care should monitor asthma attacks individuals. All individuals who have experienced a near-fatal attack should have long term asthma reviews in secondary care. The effects of hypoxaemia should be discussed with parents, children and young people. It should be included as an action point on an asthma plan.</p> | <p>Asthma guidelines (BTS/SIGN/NICE/GINA) should highlight the risk factors for near-fatal attacks/ asthma deaths which include recent attacks requiring admission. The effect on decision making due to hypoxaemia should be included within asthma guidelines and recognised as a risk factor for near fatal and fatal asthma attacks.</p> |
| Psychological impact of attacks | <p>Children and young people who have experienced a near-fatal attack should be encouraged to discuss their feelings after the attack.</p>                                                                                                                                                                                                                                               | <p>Parents/ carers/ siblings who have witnessed a near-fatal attack should be encouraged to discuss their feelings after the attack.</p>                                                                                                                                                                                                                                                  | n/a                                                                                                                                                                                  | <p>Psychological support should be offered by organisations to all individuals and their families post near-fatal attack. Trauma informed care training should be offered to clinicians.</p>                                                                                                                                                                                 | <p>Asthma guidelines (BTS/SIGN/NICE/GINA) should include a recommendation to offer all individuals and their families' psychological support post near-fatal attack.</p>                                                                                                                                                                     |

## **9.7 Strengths and limitations and methodological reflections**

To the best of my knowledge this is the first time parents and young adults have been interviewed in depth about their experience of either a fatal (parents only) or NFA attack (parents and young adults). The willingness of parents and young adults to engage with interviews, meant I was able to gain an invaluable perspective of all those involved, and the impact on the wider family. This study is unique. This was a rare group of people, and potentially hard to 'reach' due to the sensitive nature of the topic. This work was therefore important to give a voice to their experience and help shape a patient/family-centred approach to their care. We had a willingness from participant identification centre clinicians to identify potential participants, which helped aid recruitment from various geographical locations within Scotland and England. The interviews with parents related to children from early childhood to adolescence, which offered insight into how asthma management changed according to key stage development, and the challenges parents encountered with issues such as adherence. Participants were also included from all socio-economic groups, which reflects that asthma attacks and deaths can affect anyone, regardless of income or social status. This study had PPI involvement from study design and will involve PPI when disseminating the findings of the study. PPI volunteers who provided input in the planning phase of the study perceived my knowledge and skills as an experienced paediatric asthma nurse specialist, would bring a level of understanding and empathy, a non-clinical interviewer would lack. I have however reflected on my dual role in the study within section 9.7.5.

### **9.7.1 Reflections on methods.**

Carrying out this qualitative study has provided many learning opportunities. Taking time to reflect on the methods used has provided me with ideas on how to implement my new found knowledge into future studies I will conduct.

### **9.7.1.1 Recruitment**

Recruitment to this study was challenging, in particular to the fatal asthma component, when trying to identify potential participants. I had been aware of this prior to undertaking the studentship, and had spent time with clinicians and PPI volunteers discussing strategies. During the planning phase of the fatal asthma study, I had agreement from one of the leading asthma charities in the UK, to advertise for participants on their social media platforms. Although the charity remained supportive, when the time came to recruit participants, they changed the method of advertising from social media to their research volunteer's newsletter. This led to recruitment of one participant. The charity may have perceived themselves as protective gatekeepers for those on social media who had not chosen to register interest in research. The impact of this was not being able to reach families who may have been willing to participate in the study if they had been aware of it. Recruitment to the near-fatal studies was approached differently, as participants received a letter of invitation from their clinical team. This took time to co-ordinate, and involved a series of encouraging emails for clinical teams to send out information. We had no insight into how the clinical teams in the PIC sites chose who they sent information to and if potential participants had been excluded as English was not their first spoken language. However the appeal did yield a good response from those centres who could identify potential participants. Butler et al., investigated the ethical and practical realities of recruitment to bereavement research using letters (Butler et al., 2017). They explored three options using letters for recruitment: direct mailing from the research team with an opt-out option; obtaining permission via social workers who had ongoing contact with the bereaved parents; and a letter from the hospital team with an opt-in option (Butler et al., 2017). Taking into account the opinions of the participants in their study, my preferred option for recruitment for future fatal asthma studies would be to send a letter from the clinical team at the hospital with an opt-in

option. This approach has also been used by other researchers exploring experiences of bereaved parents, including a child's death from cancer, or death of a children in a paediatric intensive care unit (Steele et al., 2013, Butler et al., 2019). Any future studies exploring parent's experience of a traumatic event could utilise the use of letters to aid recruitment. It is difficult to establish if this approach would have helped with recruitment to the fatal study. The NRAD report revealed almost half of the patients who died from an asthma attack, had mild or moderate asthma and may not have been under the care of a hospital team (Levy et al., 2014). Future recruitment to fatal asthma studies would require engagement from both primary and secondary care to identify participants.

#### **9.7.1.2 Participants**

With the exception of one parent of mixed race, all participants in my study were White British. Their opinions will not be reflective of all parents or young adults who have experienced a fatal or near fatal attack within the ethnically diverse population living in the UK. According to the NRAD report, 84% of asthma deaths (adult and child) were White British (Levy et al., 2014). It is not possible to comment on the extent NFA attacks affect people from different ethnicities as there is no current database for those who have experienced a NFA attack. It is important to have culture awareness and provide education which is appropriately tailored to the individual (Ahmed et al., 2018). Ahmed et al., aimed to explore health care professionals (HCP) understanding and experiences of cultural realities that shape implementing supported, self-management for South Asians in the UK. They found that whilst professionals tried to adapt self-management strategies, due to limitations in their knowledge and ability of services to incorporate cultural factors, HCPs overgeneralised cultural realities to understand patients better, without accounting for the dynamic nature of culture in the UK. Lakhanpaul et al., also explored the asthma care of South Asian families living



in the UK alongside the care of White British families (Lakhanpaul et al., 2017). The research team investigated the perceptions and experiences of asthma and asthma management in both groups, to identify barriers to optimal management and to inform culturally appropriate interventions to improve management. Whilst both groups had similarities such as lack of understanding about asthma and medications, there were issues specific to the South Asian families. South Asian families found it more challenging to recognise asthma severity. For those with limited English there was a barrier in receiving education and understanding of how, when and where emergency management of asthma should be provided. In addition to care provision, it is also important to be aware of how those from different cultures view medications used to prevent and treat asthma symptoms. In a study exploring the use of complementary/alternative medicine (CAM) for asthma in Malaysian children, Ramdzan et al., offers insight into the health beliefs within this population (Ramdzan et al., 2019). Participants from Malay, Indian and Chinese cultures were found to use CAM as a substitute to evidence based therapies which included inhaled steroids and bronchodilators. The decision to follow this approach was often concealed from the clinicians caring for the child. This would place a child at risk of an asthma attack and possible asthma death. The use of CAM was not recognised within my study which is likely due to small number of participants and lack of ethnic diversity. Awareness of the use of CAM could open a culturally sensitive discussion regarding its use and place alongside evidence based treatments.

It would be an important area for future research to explore the experiences of parents and young people from different ethnicities relating to asthma attacks or asthma deaths. Reaching families may take greater consideration. Rather than being perceived as challenging or a hard to reach group, this may be reflective of the researcher being unfamiliar on ways to engage with different population groups. Future consideration may include discussion with religious leaders or community

based groups. This may however still remain challenging to have good representation, given the relatively small number of asthma deaths in children. Developing culturally specific educational programmes to ensure that strategies were put in place for managing asthma attacks and making sure families were aware of the serious adverse outcomes if an attack was not properly managed, may prove beneficial.

#### **9.7.1.3 Joint interview V single interview**

Within my study my intention was to conduct these all as single interviews with a parent or young adult. I was aware that some potential participants may have preferred to have a family member or friend present, to offer emotional support and was open to a joint interview approach. In the fatal study, I interviewed all participants, who were mothers, alone. Some of the fathers were present when I arrived to conduct the interview, but did not wish to take part. In the NFA attack study with parents, two were conducted as joint interviews, one of which was planned, the other happened coincidentally when the father returned home from work, and I was conducting the interview. All young adults were interviewed alone.

In my supervision sessions with MK, we discussed the possibility of interviews with both parents. As an experienced researcher in this field, MK explained how interviews with multiple people can show different sides of the needs and coping strategies of participants in their role as patient, carer, or professional (Kendall et al., 2009). In the joint interviews I conducted, one parent tended to take the lead in retelling the NFA attack. Their partner assumed a role of positively reinforcing the description of the events which took place. The parents also shared their thoughts for the future post NFA attack. One of the mothers stated her son would need to live with them forever, but the father was slightly more optimistic, which offered a brief insight into different points of views.

It is difficult to establish if joint interviews had been suggested as an option with my study, if more parents would have chosen to be interviewed together. Joint interviewing may be a worthwhile consideration in future research to encourage fathers to take part in sharing how traumatic events have affected them, in both the short and long-term. It is clear from my research however, that the potential severity of a child's asthma varied from father to mother.

#### **9.7.1.4 Timing of the parent interviews**

The time frame since either the near-fatal or fatal attack occurred varied, with some parents only six months post attack and others at the maximum time period of ten years. Some of the parents had most likely rehearsed, retold and finally consolidated their story into their version of events. This could raise the question about how true their recollection of the event was and if some important details have been excluded from their narrative. Randall and Phoenix explain that the person being interviewed can never tell us 'the whole truth' about an experience or event as a person's memories will distort over time (Randall & Phoenix, 2009). They further explain that the interview is a relationship between interviewer and participant who would each like the other to perceive them in a certain way. This will influence and change how the story is told. Acceptance that the participant was recalling their version of the event and in turn putting aside whether or not this version is the absolute truth is an important step within qualitative research. Both the PPI volunteers and the ethics committee were satisfied that a time period of up to ten years post attack was appropriate as an inclusion criteria for this study.

#### **9.7.1.5 Member checking**

Member checking, also known as respondent or participant validation, is a technique for exploring the credibility of findings (Birt et al., 2016). Prior to starting the interviews, I had a long discussion with my supervisor (MK) regarding member

checking. We discussed ownership of data and whether or not that belonged to me as the researcher, or my participants. We agreed that the interview was the participant's account of the event on that day and that this version of their story could vary, if told on another day. The area of research was a very sensitive topic and many of the participants had never shared such intimate details of their own or their child's near fatal attack or asthma death. I was concerned that reading a transcript for the first time regarding this event would cause undue upset, and could act as a trigger for an emotional event, and I had not included any 'safety netting' for participants reading transcripts in the future. I was aware of the psychological impact these events had on my participants. I made a conscious decision not to include member checking within my study.

While member checking offers the highest degree of certainty of credibility, it is not always feasible, or reasonable, to undertake this process (Rosenthal, 2016). There was a potential risk that participants may have wanted to remove some sections from the interviews which they may have felt may have shown them in a negative light. This could have included the over use of salbutamol or a delay in seeking medical review which would have impacted the findings of the study.

#### **9.7.1.6 Split role – experienced clinician versus novice researcher**

As an experienced clinician caring for children with asthma for almost 20 years it was important for me to consider how I would transition to the role of novice qualitative researcher. As my interviews were single, in depth and face to face, I was not fully prepared for the relationship between participant and researcher to end when the interview was complete. As a clinician, who had provided clinical care and emotional support for families post NFA and fatal attacks, it took some time to adjust to a very brief encounter in a family's life. Participants were aware of my clinical background, but had no expectation of ever seeing me again following the interview. Post

interviews, I spent time thinking about the families and how they must have felt and I admit I found the analysis of the interviews emotionally challenging. It was helpful to reflect on this in supervision sessions and to learn from MK who had a wealth of experience interviewing participants in a palliative stage of life. She explained her approach of being very clear with participants at the start of the interview that she would be spending a period of time conducting the interview, and after that their relationship would end. She encouraged me to keep a diary and reflect on any issues that arose in supervision sessions with all my supervisors.

Colbourne and Sque share their experience of role conflict between nurse and nurse researcher, and how the use of reflexivity and further reading helped resolve this conflict (Colbourne and Sque, 2004). Through further reading, they realised they were adopting a clinical perspective to the interviews and analysis of data, rather than considering the participant as an individual who had brief clinical contacts. This was helpful when I was conducting my interviews. Initially, I was considering how participants managed asthma from a guideline perspective rather than how they managed their or their child's asthma from a personal perspective. It also helped me consider how participants lead their lives post attacks and the psychological and emotional impact these traumatic events had. Adaptations were made to the topic guide when I learned about participant experiences which I was keen to explore further with other participants. For example, the impact on the wider family. The interviews also changed my clinical practice. Learning about the impact of a NFA attack, helped me develop a new level of empathy and helped open up topics of conversation which I hadn't considered before. These included the impact of a NFA attack on the parent's ability to sleep post attack, and the psychological impact upon a sibling when they witnessed a near-fatal event. I have also become a more cautious clinician, with a lower threshold for escalating therapy on the background of unstable asthma.

## 10 Summary and recommendations

### 10.1 Summary of PhD thesis

Asthma is a complex condition and it is increasingly acknowledged that asthma is used as an 'umbrella term' to represent different types of asthma (Pavord et al., 2018). Despite improved understanding of the condition, asthma attacks are a common daily occurrence. Within paediatric practice, there is a greater appreciation for the role previous attacks play in the risk of future attacks. Although there have been several confidential enquiries in the UK regarding asthma deaths, the number of deaths per year remains high in comparison with other developed nations, particularly in children and young people (Wolfe et al., 2014, Shah and Hagell, 2019).

The principle aim of this PhD was to examine the **Parent and Patient Perspective of Fatal and Near-Fatal Asthma**. In order to complete this assessment, the definition of near-fatal asthma required to be peer determined, through an in-depth eDelphi study. This has been completed on a global scale, and consensus has been reached within the clinical and academic community as to what constitutes a NFA attack. My research has subsequently taken this definition, and applied to criteria in my parent and patient interviews, which have sought to determine some of the identifiers associated with NFA attacks. This body of work completed component one aims (see section 2.9)

Component two of my study explored the perspectives of patients and parents who had experienced fatal or near-fatal attacks and addressed the first three of the four aims (See section 9.1). The National Review of Asthma Deaths and the British Guideline on the Management of Asthma both offer insight on known risk factors for NFA and fatal attack (Levy et al., 2014, BTS/SIGN, 2019). A previous NFA attack, previous admission to hospital, heavy/ overuse of SABA, psychological impact and clinicians' knowledge are all recognised risk factors and were discussed within the

parent and young adult interviews. Parents and young adults spoke about their asthma plan and had guidance on SABA use before they should seek medical review. As the majority of the parents and young adults had experience of hospital admission they had also been provided with weaning plans, which allowed the use of high dose SABA for a few days on discharge. The advice in the weaning plans (between 4-10 puffs SABA every 4 hours for as many as 4 days) contradicts the advice given in an asthma plan (use 10 puffs SABA and seek medical review on the same day) (See section 9.3.2). This confusion may have been a contributing factor to the high dose of SABA used at the time of the NFA or fatal attacks with some of the participants as they perceived this was the advice they had been given by a clinician. This calls for strict clarity on safe limits of SABA use as part of a self-management strategy for children and young people and young adults and for studies to be prioritised that address the benefits and risks of hospital discharge weaning plans.

Adverse behavioural or psychological features are recognised risk factors, in association with a previous NFA or previous admission however the BTS/SIGN guidelines infer these factors are specific to the patient with asthma. In my study, NFA attacks had a significant psychological impact for both the individual who experienced the attack but also for the family members who witnessed it. This impact spanned over years, and was recognised as a key event leading to change in personality, with the onset of anxiety or fear of hospital admission. It would be important to screen for effects of NFA as these factors may have an impact on a parent's ability to make a safe decision on when medical help is required in the future. Funding for psychological support services across the UK would need to be prioritised to ensure equality of care.

The NRAD report identified a lack of knowledge for some clinicians providing asthma care and this was reiterated by parents in my study. Participants felt their care providers did not always know how to recognise and treat a severe attack. The

perception was that ED clinicians may not have a uniform approach, or clinical experience/ expertise to adequately or accurately assess NFA attacks. Participants perceived asthma education lacked consistency which led to confusion when parents or young adults were faced with making decisions. This gap in clinical knowledge has been prioritised by NHS England with their plan to produce a bundle of care for children with asthma which includes capability training.

The novel findings of this study include: the power of intuition; the effect of hypoxaemia on decision making; the normalisation of asthma; and lack of awareness that asthma attacks can result in asthma death.

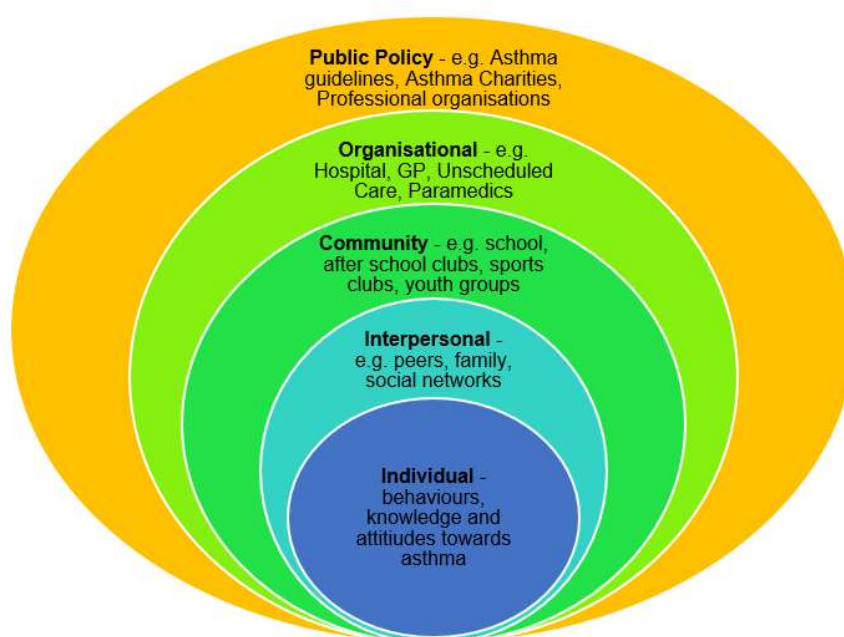
Parents and young adults talked about their intuition knowing that urgent help was needed during the fatal or near-fatal attacks but they did not always know how to act on this instinct. Discussing the role of intuition in clinic reviews may empower a parent or young adult to act on their feelings with future attacks. It is also important to consider the distortion that hypoxaemia may bring to that intuitive feeling and the discordant decision making this may produce between young adults and their parents at key stages in a NFA attack. Scenarios for adolescents and young adults may prove beneficial to establish how they would manage an attack if they were the sole decision maker at the time, ensuring they had awareness of the impact hypoxaemia would have on these decisions. Parents and young adults offered insight into their lives managing asthma on a daily basis and how the condition was incorporated into everyday life subconsciously. This led to the normalisation of asthma and the 'it's just asthma' attitude. This attitude was reinforced by family, friends, education, clinicians and the general public. Changing attitudes will require time however unless this attitude changes patients with asthma will not truly recognise the risks associated with the condition. Participants openly discussed the ongoing impact of living with bereavement. They also discussed the risk of their child, or for the young adults the personal risk, of having another NFA attack. Knowledge of asthma and the



associated risk of an asthma related death was poorly understood by participants and this highlights the need to improve awareness of this risk. The taboo around asthma deaths needs to be removed and lessons need to be learned from other conditions such as epilepsy and anaphylaxis who ensure all patients and families are aware of this potential outcome.

Changes are required if asthma attacks and asthma deaths are to reduce. By applying the socio-ecological model as the underpinning framework for this study we can appreciate this will involve engagement not only from individuals, their families, the community and organisations but also involvement from key stakeholders, such as commissioners, NHS boards and asthma charities (figure 35). There are potential implications, subject to further research or development of training programmes, to inform key stakeholders such as education, primary care, severe asthma registries and emergency service responses. These are highlighted in the recommendations and address the fourth aim of component two of my study.

**FIGURE 35 SOCIO-ECOLOGICAL MODEL DISPLAYING THE MULTILEVEL FACTORS THAT COULD REDUCE NEAR FATAL ATTACKS AND PREVENT ASTHMA DEATHS IN CHILDREN AND YOUNG PEOPLE**  
Adapted from Nuss et al., 2016



## **10.2 Recommendations**

Overall, I have considered the findings from the eDelphi study in component one of this study and the findings from the qualitative study in component two. Recommendations for multiple groups and for future research are provided below.

### **10.2.1 For individuals with asthma**

The findings from the qualitative interviews in this PhD have implications for how care is provided for people living asthma:

- Post attack reviews should be offered routinely and conducted by a member of staff who has received appropriate capability based training.
- Asthma plans should be provided and developed in partnership with all patients and their families with very strict clarity as to the maximum amount of bronchodilator to be used before getting medical help.
- Patients who have had a NFA attack should have a planned in person structured review in a tertiary centre multi-disciplinary team which includes consultant, specialist nurse, physiology and psychology.
- Development of an asthma death discussion pathway for all patients and families.
- Creation of a virtual ward when a child or young person is discharged from hospital. Support and guidance could be offered whilst the child remains on a weaning dose of salbutamol until fully recovered and provided via the NHS Attend Anywhere virtual platform.

### **10.2.2 For families, friends and social groups caring for individuals with asthma**

The findings of this PhD have implications for families, friends and social groups who care for any child or young person with asthma.

- Education for fathers (or mothers) of children with asthma who may not have the opportunity to attend asthma reviews.
- Education for all adults who have a role of responsibility in a child's life to ensure they can recognise and treat an asthma attack with clear guidance on when to call for medical help.

### **10.2.3 Community services**

The findings of this PhD have implications for those providing asthma care in the community which includes local pharmacists, school nursing and primary care staff.

- Development of local resources to engage with children, young people and their families on asthma management.
- Mandatory implementation of the emergency inhalers in schools policy.
- Development of group consultations for children and young people in schools focussing on asthma education.

### **10.2.4 For professionals and clinical services**

The findings of this PhD have implications for professionals and clinical services.

- Professionals caring for children with asthma should have appropriate knowledge and skills measured against a competency/ capability framework.
- Professionals caring for children with asthma should be able to recognise risks including those that may result in asthma deaths.
- Professionals caring for children, teenagers and young adults should take part in regular scenario based training on the management of a NFA attack. This should include decision making in a variety of settings e.g. GP surgery, in a family home, in a ward etc.
- Professionals should discuss the impact hypoxaemia may have on decision making during a severe asthma attack.

- Professionals should engage parents and young adults in discussion of an asthma death and how to avoid it.
- Professionals should be aware that the interpretation of an asthma plan may diverge with time and that an open discussion on this topic should be repeated regularly.
- Professionals should have access to training on loss and grief.
- Professionals should have access to trauma-informed care training.
- Professionals should have access to ethnic and cultural awareness and communications training
- An alert should be placed on the ambulance service database alerting paramedics that the child had a NFA attack in the past.

#### **10.2.5 Organisations**

The findings of this PhD have implications for organisations.

- Organisations should ensure equitable access to asthma training for all professionals. This could be accessed from a recommended education provider or developed locally.
- Identification of a lead clinician for asthma in each organisation.

#### **10.2.6 For policy makers**

The findings of the eDelphi and qualitative study have implications for policy makers.

- Adoption of the consensus definition of Near-Fatal Asthma by the British Thoracic Society, The Scottish Intercollegiate Guidelines Network and The National Institute for Clinical Excellence and incorporated in their Asthma Guideline in the UK.
- Adoption of the consensus definition of Near-Fatal Asthma by Global Initiative for Asthma to incorporate the consensus definition into the Asthma Strategy.

- Recognition of the term Near-Fatal Asthma by the World Health Organisation International Classification of Diseases.
- Provide better support for multidisciplinary review of asthma.
- Provide better psychological service provision to those affected by near-fatal and fatal asthma (CYP, young adults, parents and siblings).

#### **10.2.7 For research**

A number of areas have been identified in this thesis, suggesting directions for future research for children, young people and young adults affected by near fatal asthma attacks. Recommendations for research include:

The eDelphi study agreed a consensus definition for near-fatal asthma and has implications for future research.

- Researchers can recruit participants to a study who will meet agreed consensus definition.
- The incidence of near-fatal asthma could be measured against these criteria.
- Ongoing surveillance of those affected by a near-fatal asthma attack could be undertaken. This could identify demographics of patients, medications taken, subsequent attacks and longer term outcomes.

Other research priorities could include:

- Research to assess the benefits and risks of hospital discharge weaning plans.
- Research to explore the benefits and risks of using a pulse oximeter for children and young people as part of their asthma plan.
- Future qualitative studies on experiences of asthma attacks or asthma deaths from a more diverse population.

### **10.3 Final thought.**

As I was leaving a home following an interview with a parent whose son had died from an asthma attack she said, "*It's not something in this day and age that should take so many lives, really.*" I have used this quotation in presentations as a final thought, we should aim for a zero tolerance on asthma attacks and asthma deaths.

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# Appendices

## APPENDIX 1: ETHICAL APPROVAL FROM USHER



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### USHER RESEARCH ETHICS GROUP

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19 January 2018

Ms Ann McMurray

Dear Ann

**Re: An eDelphi consensus study of Near Fatal Asthma in children, young people and young adults.**

Thank you for resubmitting your revised application for above study, with the further information and clarification/ revisions that were requested by the Usher Research Ethics Group (UREG). The revised application has been reviewed by the Usher Research Ethics Group (UREG) and an Usher colleague, and judged satisfactory. We are therefore pleased to be able to inform you that the study has been granted ethics approval.

Please be aware that this ethical approval is in respect of the protocol and methods as described in the REV2 documents submitted to the committee (with amended documents superseding predecessors). If there is in the future *a change* to the study design/protocol/methods, you should check with UREG whether this means your level 2 application form needs to be **amended**.<sup>1</sup>

Best wishes for your research.

Yours sincerely

**Diane White**

**Usher Research Ethics Group Administrator**

<sup>1</sup> Guidance for **amendments** can be found in the Usher shared area, in doc 'Amendment Guidance' at path U:\Datastore\CMVM\smgphs\shared\Usher\ResAdmin\ETHICSdocsForms\CPHS Ethics Group docs



UREG Ethics Intranet : <http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php> (Staff & PGR Students only)

Usher: <http://www.ed.ac.uk/usher/>

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## APPENDIX 2: EMAIL INVITATION TO POTENTIAL PARTICIPANTS

Invitation email to participants



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Asthma UK Centre  
for Applied Research



### The end of the spectrum for asthma attacks – Near Fatal Asthma

#### An eDelphi study to gain consensus definition of Near Fatal Asthma.

We are writing to you as someone with experience of treating severe exacerbations of asthma as we need your help to answer an important question – can we define Near Fatal Asthma (there is currently no agreed definition). If that can be agreed then it would be possible to measure such events more precisely and enable trials of interventions. We are aware that people who experience such events are at high risk of future morbidity and mortality so it is a vital group to understand.

Whilst asthma guidelines, such as Global Initiative for Asthma (GINA) and BTS/SIGN, categorise the severity of asthma attacks into mild, moderate and severe, many clinicians also recognise another penultimate attack which, if not recognised by the individual, parent or carer and then skilfully treated by a clinical team, would result in death. Status asthmaticus is used within Medical Subject Headings (MeSH) and ICD-10 (medical coding) however this term lacks definition. Clinical guidelines do not have consensus for penultimate attacks in asthma.

**Aim of the Delphi** - To gain international clinical consensus definition for this penultimate attack and an appropriate name to enable the frequency of defined attacks to be measured, against which future interventions can be trialled to reduce these and asthma deaths.

**Population** - Please consider children from age 5 to young adults aged 24. We have selected this age range to ensure appropriate diagnosis in the young child and exclude co morbidities in the older adult.

We are only asking Medical Staff who are of Consultant/ Board Certified status, qualified in the fields of respiratory, emergency department and intensive care medicine to take part in the study. The eDelphi will consist of three rounds. Following each round, those contributing will be provided with a summary to inform the next round. Those completing all three rounds will be provided with the summary results of the Delphi process. In our test trials of the first round the survey took **no longer than 15 minutes** for clinicians to complete. Completing all three rounds will greatly enhance the quality of the Delphi, so please stick with it – later rounds should be briefer than this first round.

The e delphi study will be led by a PhD student working within the Asthma UK Centre for Applied Research based at the University of Edinburgh. <https://www.aukcar.ac.uk/people/phd-student/ann-mcmurray>

We all appreciate your help and support with this study, please contact us if you have questions.

Many thanks in anticipation

Ann, Steve and Louise

Ann McMurray (ann.mcmurray@ed.ac.uk)

Professor Steve Cunningham (steve.cunningham@ed.ac.uk)

Dr Louise Fleming (l.fleming@rbht.nhs.uk)

## APPENDIX 3: PARTICIPANT INFORMATION SHEET FOR eDELPHI



### eDelphi Study Information Sheet

We would like to invite you to take part in an eDelphi consensus study. Before you decide whether or not you would like to take part, it is important for you to consider why this research is being done and what it will involve. Please read this information sheet carefully.

#### **What is a Delphi study?**

The Delphi technique seeks to obtain consensus on the opinions of experts, termed panel members, through a series of structured questionnaires. As part of the process, the responses from each round are fed back in summarised form to the participants who are then given an opportunity to respond again to emerging data. The Delphi is therefore an iterative multi-stage process designed to combine opinion into group consensus.

#### **What is the purpose of this study?**

National and international asthma guidelines, such as BTS/SIGN and GINA, categorise the severity of asthma attacks into mild, moderate and severe/life threatening episodes with guidance on clinical signs and objective measurements identified for each. Patients in general will be unaware which category their asthma attacks falls and many who experience a severe asthma attack are not considered by clinicians at immediate risk of death.

In those who experience a particularly severe asthma attack there is a penultimate event which, if not recognised by the individual, parent or carer and then skilfully treated by a clinical team, will result in death. Status asthmaticus is the term used to describe this event within Medical Subject Headings (MeSH) and ICD-10 (medical coding) however this term lacks consistent definition and, in a proportion of studies, has been superseded with other terms which include near fatal asthma, severe life threatening asthma with progressive respiratory failure and critical asthma syndrome. There is evidence that those individuals who have experienced such an event are at significant risk of experiencing a similar attack in the future or death.

#### **What is the aim of the Delphi?**

To gain an international clinical consensus definition for this penultimate attack (referred to as a critical attack in the eDelphi) and an appropriate name to enable the frequency of defined attacks to be measured, against which future interventions can be trialled to reduce these and asthma deaths.

#### **Why have I been invited to take part?**

As an established expert in your field we are keen to gain your views about clinical signs, objective measurements and other key factors which you feel are important in defining a near fatal asthma attack. We are only asking Medical Staff who are of Consultant/ Board Certified status, qualified in the fields of respiratory, emergency department and intensive care medicine to take part in the study.

#### **What will I be asked to do if I take part?**

We are inviting you to participate as a Delphi panel member. This would involve completing a brief questionnaire, rating possible clinical features, objective measurements and other factors relating to a near fatal asthma attack using an online survey. It is envisaged that this should take approximately 15 minutes. You would subsequently receive a reminder of your ratings, a summary of the group's responses and a further online questionnaire to re-rate the original list. This process would continue until a group consensus is achieved or three Delphi rounds have been completed. In order to allow

eDelphi study information version 1.0





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London



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timely conclusion of the study we would respectfully request a response time of 1 week for completion of each round.

#### Who is organising and funding the research?

The e delphi study will be led by a PhD student working within the Asthma UK Centre for Applied Research based at the University of Edinburgh. <https://www.aukar.ac.uk/people/phd-student/ann-mcmurray> Professor Steve Cunningham and Dr Louise Fleming will supervise her. This work is funded by The University of Edinburgh, College of Medicine and Veterinary Medicine PhD Studentship (Asthma UK Centre for Applied Research PhD/15/01).

#### Confidentiality

The survey responses will be collated anonymously using an identifying number known only to the participant and lead investigator. All responses received in the study will be strictly confidential, and your identity will not be divulged. Direct quotes to free-text answers may be used as part of the study report or later Delphi iterations, but these will be not be traceable back to you.

#### Data protection

Survey responses will be collected online using Bristol online surveys which is fully compliant with all UK data protection laws. Results will be downloaded to an encrypted University of Edinburgh laptop to allow analysis by the research team. All data will be archived for 5 years and then destroyed in accordance with the University of Edinburgh policy for destroying archived research data. Professor Steve Cunningham will be a named contact.

#### Ethics

The Usher Research Ethics Group, University of Edinburgh have granted ethically approval for this study.

#### Consent

All participants will consent digitally on page one of the e Delphi. Although we would encourage all participants to complete all three rounds of the Delphi they are free to withdraw consent at any stage.

#### Complaints

If you wish to make a complaint about the study please contact Professor Sarah Cunningham-Burley, Dean of Molecular, Genetic and Population Health Sciences at the University of Edinburgh on [Sarah.C.Burley@ed.ac.uk](mailto:Sarah.C.Burley@ed.ac.uk).

#### What do I do now?

Thank you for reading this information sheet and considering taking part in this research. If you would like to participate please use the link in the email invitation.

If you have any questions or concerns please do not hesitate to contact me on [nearfatalasthma@ed.ac.uk](mailto:nearfatalasthma@ed.ac.uk).

[ed.ac.uk](mailto:ed.ac.uk)

|              |                            |                   |
|--------------|----------------------------|-------------------|
| Ann McMurray | Professor Steve Cunningham | Dr Louise Fleming |
| PhD Student  | Supervisor                 | Supervisor        |

eDelphi study information version 1.0

#### APPENDIX 4: YOUNG ADULT PERSPECTIVE OF A NEAR FATAL ASTHMA ATTACK, PARTICIPANT INFORMATION SHEET DISTRIBUTED BY PIC.



THE UNIVERSITY  
of EDINBURGH



Asthma UK Centre  
for Applied Research



Imperial College  
London

### Young adult perspective of a near fatal asthma attack Participant Information Sheet

You are being invited to take part in a research study. Before you decide, it is important to know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### What is the research about?

Every 10 seconds someone with asthma is having an asthma attack. Doctors and nurses have asthma guidelines which help them decide how bad an attack is depending on things like how fast you breathe, how quickly your heart beats and how wheezy you are. They then call an attack mild, moderate or severe. There is another type of attack which is so bad it can make you stop breathing or stop your heart beating and if it wasn't treated at the right time you could die. This gets mixed up with the severe group, but is different and is sometimes called a near fatal asthma attack. Although doctors and nurses know some of the reasons why people have a near fatal asthma attack, very few researchers have asked young adults to tell their story of what happened. We would like you to tell us about your asthma care and what made this asthma attack different from attacks which had happened before. We hope to learn from you and make changes to the way we educate patients and families about asthma and how to manage attacks. Hopefully over time this will help prevent these type of attacks and asthma deaths.

#### Who is organising and funding the research?



Ann McMurray is a PhD student from the University of Edinburgh and will be leading the discussions. She has worked as an asthma nurse specialist in the NHS for the past 16 years. She will be supervised by Dr Marilyn Kendall and Professor Steve Cunningham from the University of Edinburgh and Dr Louise Fleming from Imperial College, London. Ann McMurray's PhD is funded by the University of Edinburgh and is linked to the work carried out by the Asthma UK Centre for Applied Research.

#### Why have I been asked to take part?

You have been asked to take part as sadly your child, who was aged between 5 years old and 24 years old, died due to an asthma attack. This attack will have taken place within the last 10 years and you were with your child when it happened. We are keen to speak to families throughout the UK. If you would like to take part our researcher will confirm these details with you before we make any further arrangements.

#### Do I have to take part?

No, it is up to you to decide whether or not to take part. If you think you might be interested in taking part please contact the research team using the details at the end of this leaflet. They will be happy to answer any questions you have about the study and will organise to meet you for the discussion. If you decide to take part you are still free to withdraw at any time, and without giving any reason. Please just let the research

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19.02.18

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team know you do not want to take part any more. You can do this by email, text or phoning. A decision not to take part, or to withdraw at any time, will not affect the standard of care you currently receive from the Health Service.

#### **What will happen if I take part in the research study?**

If you would like to take part our researcher (Ann McMurray) will arrange a suitable time to come and talk to you, at a place that is convenient to you. This will either be at your home or a local community venue. If you need to travel to a venue we will pay for your expenses. This will be quite informal, where you will be encouraged to talk about your experiences. You don't have to answer all the questions if you don't want to – we are keen to hear your views in your own words. The discussion will last about an hour, depending on how much we have to talk about. The researcher will ask your permission to record the discussion with a digital recorder so that the research team can listen to these and write them up afterwards. Your name and any other information that you provide in the discussion which might identify you will be removed or changed so that you can't be recognised.

#### **Are there any benefits in taking part?**

The discussion will involve talking about issues that are important to you and give you the chance to share your experiences. The study may not have any direct or immediate benefit to you but we hope that the information we get from you may help us develop better care for other people with asthma.

#### **Are there any disadvantages or risks in taking part?**

Sometimes people can become upset when they discuss personal thoughts or feelings about issues which are important to them. The researcher will ensure that your thoughts and feelings are respected at all times. If you feel you would like to stop or take a break just let the researcher know and they will stop the recorder for as long as you need, or end the discussion there. We will also make sure that you know who you can contact for any advice, if you feel you would like, because of what you discussed with the researcher.

#### **What happens when the research study stops?**

After the discussion with the researcher, your involvement in the study will end. We will write up a summary of study findings and can send you a copy if you wish. In the future the anonymised transcripts of our discussion may be used in other ethically approved studies.

#### **Will my taking part be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. In order to monitor and audit the study we ask your consent for responsible representatives from the sponsors and NHS Institutions to access your data collected during the study, where it is relevant to you taking part in this research. The Sponsors are responsible for overall management of the study and providing insurance and indemnity. With your consent we will inform your GP and hospital team that you are taking part.

#### **How will my information be stored?**

After the discussion the encrypted audio recording will be sent to 1<sup>st</sup> Class Secretarial, a third party contractor for transcription. Once completed the typed transcript of our

Young adult perspective of Near Fatal Asthma Study Participant Information Sheet version 1

19.02.18

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monitor and audit the study we ask your consent for responsible representatives from the sponsors and NHS Institutions to access your data collected during the study, where it is relevant to you taking part in this research. The Sponsors are responsible for overall management of the study and providing insurance and indemnity. With your consent we will inform your GP and hospital team that you are taking part.

#### **Are there times when you may need to share my information with other professionals?**

What you say in the discussion is kept confidential by the research team but you may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have an obligation to report. If you do say something like this, then after the discussion has ended the researcher may talk to you about sharing this information, and whilst preserving your confidentiality take advice from other members of the research team.

#### **How will my information be stored?**

After the discussion the encrypted audio recording will be sent to 1<sup>st</sup> Class Secretarial, a third party contractor for transcription. Once completed the typed transcript of our discussion will be stored on a password-protected computer. The recordings will be deleted after the study is completed. The transcripts may be archived in an anonymous form (this means without any information that could be used to identify you). Your name and address will be stored on an NHS computer and you will be given a study number. The transcripts will be stored on a University Computer with your study number and will be stored for 5 years after the study is complete. All data is handled in accordance with the University of Edinburgh's data handling and storage policies. Any information that you provide to the research team and everything you say in the discussion will be kept strictly confidential. Only the researcher will see this information.

#### **What happens if I don't want to continue the study?**

If you don't want to carry on with the study you can withdraw at any time even after you have met with the researcher and had a discussion. Please just let the research team know that you do not want to take part any more. You can do this by phone or by email or text (simply send us a text/email with your name and write "Stop interview".) You do not need to give a reason. Taking part in the study, or not taking part in the study, will not affect the care that you currently receive from the Health Service.

#### **What will happen to the results of the study?**

At the end of the study we will send you a summary of our findings either by email or post. Findings will be presented at conferences, training events, published in a journal and will contribute towards the submission of a Doctorate in Philosophy degree (PhD). Quotes from the discussion will be used in publications however you will not be identified in any of these.

#### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a research ethics committee. A favourable ethical opinion has been obtained from West



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of Scotland Research Ethics Committee 3 (WoSREC3) . NHS management approval has also been given.

**Who will sponsor the study?**

The study is sponsored by the University of Edinburgh and NHS Lothian.

**For further information on the study and to take part please contact:**

Ann McMurray  
PhD Student  
Centre for Population Health Sciences  
University of Edinburgh  
Teviot Place  
Edinburgh  
EH8 9AG  
Telephone: 07976582297  
Email: [ann.mcmurray@ed.ac.uk](mailto:ann.mcmurray@ed.ac.uk)

If you have any concerns or questions about any part of the research, you can speak with an independent person who is not involved in the study:

Julie Westwood, NHS Lothian

[@nhslothian.scot.nhs.uk](mailto:@nhslothian.scot.nhs.uk) Telephone: 0131 536 0773

Complaints – if you wish to make a complaint about the study please contact:  
[resgov@accord.scot](mailto:resgov@accord.scot)

**Thank you for taking time to read this information sheet.**



**APPENDIX 5: PARENT/ CARER PERSPECTIVE OF A NEAR FATAL ASTHMA ATTACK, PARTICIPANT INFORMATION SHEET DISTRIBUTED BY PIC.**



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**Parent or carer perspective of a near fatal asthma attack  
Participant Information Sheet**

You are being invited to take part in a research study which will involve a face to face discussion lasting about an hour. Before you decide, it is important to know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the research about?**

Every 10 seconds someone with asthma is having an asthma attack. Doctors and nurses have asthma guidelines which help them decide how bad an attack is depending on things like how fast you breathe, how quickly your heart beats and how wheezy you are. They then call an attack mild, moderate or severe. A severe attack is bad but one from which most people with usual treatments make a full recovery. There is another type of attack which is so bad it can make you stop breathing or your heart stop and if it's not treated at the right time you can die. This gets mixed up with the severe group, but is thought to be different, and is sometimes called a near fatal asthma attack. Although doctors and nurses know some of the reasons why people have a near fatal asthma attack, very few researchers have asked parents to tell their story of what happened. We would like you to tell us about your child's asthma care and what, if anything, made this asthma attack different from attacks which had happened before. We hope to learn from you and make changes to the way we educate patients and families about asthma and how to manage attacks. Hopefully over time this will help prevent these type of attacks and/ or change treatment to reduce asthma deaths.

**Who is organising and funding the research?**



Ann McMurray is a PhD student from the University of Edinburgh and will be leading the discussions. She has worked as an asthma nurse specialist in the NHS for the past 16 years. She will be supervised by Dr Marilyn Kendall and Professor Steve Cunningham from the University of Edinburgh and Dr Louise Fleming from Imperial College, London. Ann McMurray's PhD is funded by the University of Edinburgh and is linked to the work carried out by the Asthma UK Centre for Applied Research.

**Why have I been asked to take part?**

You have been asked to take part in this study as we understand your child, who was aged between 5 years old and 24 years old at the time, had a very severe asthma attack which the doctors may have called life threatening or a near fatal asthma attack. This means your child will most likely have been in the Intensive Care Unit. This attack will have taken place within the last 10 years and you were with your child when it happened. We are keen to speak to families throughout the UK. Your asthma team has sent this information leaflet to you but they have not shared any of your details with us.

**Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you think you might be interested in taking part please contact the research team using the details at the end of this leaflet.



They will be happy to answer any questions you have about the study and will organise to meet you for the discussion. If you decide to take part you are still free to withdraw at any time, and without giving any reason. Please just let the research team know you do not want to take part any more. You can do this by email, text or phoning. A decision not to take part, or to withdraw at any time, will not affect the standard of care you currently receive from the Health Service.

#### **What will happen if I take part in the research study?**

If you would like to take part our researcher (Ann McMurray) will arrange a suitable time to come and talk to you, at a place that is convenient to you. This will either be at your home or a local community venue. If you need to travel to a venue we will pay for your expenses. This will be quite informal, where you will be encouraged to talk about your experiences. You don't have to answer all the questions if you don't want to – we are keen to hear your views in your own words. The discussion may last up to 2 hours, depending on how much we have to talk about. The researcher will ask your permission to record the discussion with a digital recorder so that the research team can listen to these and write them up afterwards. Your name and any other information that you provide in the discussion which might identify you will be removed or changed so that you can't be recognised.

#### **Are there any benefits in taking part?**

The discussion will involve talking about issues that are important to you and give you the chance to share your experiences. The study may not have any direct or immediate benefit to you but we hope that the information we get from you may help us develop better care for other people with asthma.

#### **Are there any disadvantages or risks in taking part?**

Sometimes people can become upset when they discuss personal thoughts or feelings about issues which are important to them. The researcher will ensure that your thoughts and feelings are respected at all times. The discussion may take up to two hours which is a long time so we will need to take some breaks. If you feel you would like to stop or take a break just let the researcher know and they will stop the recorder for as long as you need, or end the discussion there. You can take as many breaks as you need. We will also make sure that you know who you can contact for any advice, if you feel you would like, because of what you discussed with the researcher. These will include contact numbers for your hospital team, Asthma UK Nurses helpline and your GP. If you are still upset after the discussion the researcher will stay with you until a family member or friend can be with you. The researcher will contact you the following day to make sure you have some support in place or answer any questions you may have.

#### **What happens when the research study stops?**

After the discussion with the researcher, your involvement in the study will end. We will write up a summary of study findings and can send you a copy if you wish. In the future the anonymised transcripts of our discussion may be used in other ethically approved studies.

#### **Will my taking part be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. In order to monitor and audit the study we ask your consent for responsible representatives from the sponsors and NHS Institutions to access your data collected during the study, where it is relevant to you.





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taking part in this research. The Sponsors are responsible for overall management of the study and providing insurance and indemnity. With your consent we will inform your GP and hospital team that you are taking part.

#### **Are there times when you may need to share my information with other professionals?**

What you say in the discussion is kept confidential by the research team but you may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have an obligation to report. If you do say something like this, then after the discussion has ended the researcher may talk to you about sharing this information, and whilst preserving your confidentiality take advice from other members of the research team.

#### **How will my information be stored?**

After the discussion the encrypted audio recording will be sent to 1<sup>st</sup> Class Secretarial, a third party contractor for transcription. Once completed the typed transcript of our discussion will be stored on a password-protected computer. The recordings will be deleted after the study is completed. The transcripts may be archived in an anonymous form (this means without any information that could be used to identify you). Your name and address will be stored on an NHS computer and you will be given a study number. The transcripts will be stored on a University computer with your study number and will be stored for 5 years after the study is complete. All data is handled in accordance with the University of Edinburgh's data handling and storage policies. Any information that you provide to the research team and everything you say in the discussion will be kept strictly confidential. Only the researcher will see this information.

#### **What happens if I don't want to continue the study?**

If you don't want to carry on with the study you can withdraw at any time even after you have met with the researcher and had a discussion. Please just let the research team know that you do not want to take part any more. You can do this by phone or by email or text (simply send us a text/email with your name and write "Stop interview".) You do not need to give a reason. Taking part in the study, or not taking part in the study, will not affect the care that you currently receive from the Health Service.

#### **What will happen to the results of the study?**

At the end of the study we will send you a summary of our findings either by email or post. Findings will be presented at conferences, training events, published in a journal and will contribute towards the submission of a Doctorate in Philosophy degree (PhD). Quotes from the discussion will be used in publications however you will not be identified in any of these.

#### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a research ethics committee. A favourable ethical opinion has been obtained from West of Scotland Research Ethics Committee 3 (WoSREC3). NHS management approval has also been given.

#### **Who will sponsor the study?**

The study is sponsored by the University of Edinburgh and NHS Lothian.



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**For further information on the study and to take part please contact:**

Ann McMurray  
PhD Student  
Centre for Population Health Sciences  
University of Edinburgh  
Teviot Place  
Edinburgh  
EH8 9AG  
Telephone: 07976582297  
Email: [ann.mcmurray@ed.ac.uk](mailto:ann.mcmurray@ed.ac.uk)

If you have any concerns or questions about any part of the research, you can speak with an independent person who is not involved in the study:

Julie Westwood, NHS Lothian  
[Julie.Westwood@nhslothian.scot.nhs.uk](mailto:Julie.Westwood@nhslothian.scot.nhs.uk)  
0131 536 0773

Complaints – if you wish to make a complaint about the study please contact;  
[resgov@accord.scot](mailto:resgov@accord.scot)

Thank you for taking time to read this information leaflet.

## APPENDIX 6: PARENT/ CARER PERSPECTIVE OF A FATAL ASTHMA ATTACK, PARTICIPANT INFORMATION SHEET.



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### Parent or carer perspective of a fatal asthma attack Participant Information Sheet

You are being invited to take part in a research study which will involve a face to face discussion lasting about up to 2 hours. Before you decide, it is important to know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### What is the research about?

Each day 3 people die from asthma in the UK. Although doctors and nurses know some of the reasons why people die from an asthma attack, very few researchers have asked parents to tell their story of what happened. We would like you to tell us about your child's asthma care, what effect asthma had on your lives, about your family home and living environment and what happened during the final attack. We hope to learn from you and make changes to the way we educate patients and families about asthma and how to manage attacks. Hopefully over time this will help prevent asthma deaths.

#### Who is organising and funding the research?



Ann McMurray is a PhD student from the University of Edinburgh and will be leading the discussions. She has worked as an asthma nurse specialist in the NHS for the past 16 years. She will be supervised by Dr Marilyn Kendall and Professor Steve Cunningham from the University of Edinburgh and Dr Louise Fleming from Imperial College, London. Ann McMurray's PhD is funded by the University of Edinburgh and is linked to the work carried out by the Asthma UK Centre for Applied Research.

#### Why have I been asked to take part?

You have been asked to take part as sadly your child, who was aged between 5 years old and 24 years old, died due to an asthma attack. This attack will have taken place within the last 10 years and you were with your child when it happened. We are keen to speak to families throughout the UK. If you would like to take part our researcher will confirm these details with you before we make any further arrangements.

#### Do I have to take part?

No, it is up to you to decide whether or not to take part. If you think you might be interested in taking part please contact the research team using the details at the end of this leaflet. They will be happy to answer any questions you have about the study and will organise to meet you for the discussion. If you decide to take part you are still free to withdraw at any time, and without giving any reason. Please just let the research team know you do not want to take part any more. You can do this by email, text or phoning. A decision not to take part, or to withdraw at any time, will not affect the standard of care you currently receive from the Health Service.

#### What will happen if I take part in the research study?

If you would like to take part our researcher (Ann McMurray) will arrange a suitable time to come and talk to you, at a place that is convenient to you. This will either be at your home or a local community venue. If you need to travel to a venue we will pay for your expenses.

Fatal Asthma Study Participant Information sheet

V1.1 08.05.18

IRAS 237440





This will be quite informal, where you will be encouraged to talk about your experiences. You don't have to answer all the questions if you don't want to – we are keen to hear your views in your own words. The discussion may last up to 2 hours, depending on how much we have to talk about. The researcher will ask your permission to record the discussion with a digital recorder so that the research team can listen to these and write them up afterwards. Your name and any other information that you provide in the discussion which might identify you will be removed or changed so that you can't be recognised.

#### **Are there any benefits in taking part?**

The discussion will involve talking about issues that are important to you and give you the chance to share your experiences. The study may not have any direct or immediate benefit to you but we hope that the information we get from you may help us develop better care for other people with asthma. There is still a lot of research required to stop asthma deaths and this is only a small study which will not solve the problem. We would however really value your input so we can start to improve our understanding of what happens during these fatal attacks.

#### **Are there any disadvantages or risks in taking part?**

Sometimes people can become upset when they discuss personal thoughts or feelings about issues which are important to them. The researcher will ensure that your thoughts and feelings are respected at all times. The discussion may take up to two hours which can seem like a long time so we will need to take some breaks, just let the researcher know and they will stop the recorder for as long as you need, or end the discussion there. You can take as many breaks as you need. We will also make sure that you know who you can contact for any advice, if you feel you would like, because of what you discussed with the researcher. These will include contact numbers for Asthma UK Nurses helpline, Child Bereavement UK, Cruse and your GP. If you are still upset after the discussion has ended the researcher will stay with you until a family member or friend can be with you. The researcher will contact you the following day to make sure you have some support in place or answer any questions you may have.

#### **What happens when the research study stops?**

After the discussion with the researcher, your involvement in the study will end. We will write up a summary of study findings and can send you a copy if you wish. In the future the anonymised transcripts of our discussion may be used in other ethically approved studies.

#### **Will my taking part be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. In order to monitor and audit the study we ask your consent for responsible representatives from the sponsors and NHS Institutions to access your data collected during the study, where it is relevant to you taking part in this research. The Sponsors are responsible for overall management of the study and providing insurance and indemnity. With your consent we will inform your GP that you are taking part.

#### **Are there times when you may need to share my information with other professionals?**

What you say in the discussion is kept confidential by the research team but you may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have an obligation to report. If you do say something like this, then after the discussion has ended the researcher may talk to you about sharing

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this information, and whilst preserving your confidentiality take advice from other members of the research team.

#### **How will my information be stored?**

After the discussion the encrypted audio recording will be sent to 1<sup>st</sup> Class Secretarial, a third party contractor for transcription. Once completed the typed transcript of our discussion will be stored on a password-protected computer. The recordings will be deleted after the study is completed. The transcripts may be archived in an anonymous form (this means without any information that could be used to identify you). Your name and address will be stored on an NHS computer network and you will be given a study number. The transcripts will be stored on a University network with your study number and will be stored for 5 years after the study is complete. All data is handled in accordance with the University of Edinburgh's data handling and storage policies. Any information that you provide to the research team and everything you say in the discussion will be kept strictly confidential. Your name and address will be kept separately from your interview. Only the researcher will see this information.

#### **What happens if I don't want to continue the study?**

If you don't want to carry on with the study you can withdraw at any time even after you have met with the researcher and had a discussion. Please just let the research team know that you do not want to take part any more. You can do this by phone or by email or text (simply send us a text/email with your name and write "Stop interview".) You do not need to give a reason. Taking part in the study, or not taking part in the study, will not affect the care that you currently receive from the Health Service.

#### **What will happen to the results of the study?**

At the end of the study we will send you a summary of our findings either by email or post. Findings will be presented at conferences, training events, published in a journal and will contribute towards the submission of a Doctorate in Philosophy degree (PhD). Quotes from the discussion will be used in publications however you will not be identified in any of these

#### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a research ethics committee. A favourable ethical opinion has been obtained from A favourable ethical opinion has been obtained from West of Scotland Research Ethics Committee 3 (WoSREC3). NHS management approval has also been given.

#### **Who will sponsor the study?**

The study is sponsored by the University of Edinburgh and NHS Lothian.

#### **For further information on the study and to take part please contact:**

Ann McMurray  
PhD Student  
Centre for Population Health Sciences  
University of Edinburgh  
Teviot Place  
Edinburgh  
EH8 9AG  
Telephone: 07976582297  
Email: ann.mcmurray@ed.ac.uk

Fatal Asthma Study Participant Information sheet  
V1.1 08.05.18  
IRAS 237440



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If you have any concerns or questions about any part of the research, you can speak with an independent person who is not involved in the study:

Julie Westwood, NHS Lothian

Julie.Westwood@nhslothian.scot.nhs.uk

0131 536 0773

Complaints – if you wish to make a complaint about the study please contact;  
[resgov@accord.scot](mailto:resgov@accord.scot)

Thank you for taking time to read this information leaflet.

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## APPENDIX 7: CONSENT FORM FOR YOUNG ADULT NFA STUDY



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IRAS ID: 237440

Patient Identification Number for this study:

### Participant Consent Form

Title of Project: Young adult personal perspective of a near fatal asthma attack

Name of Researcher: Ann McMurray

Please Initial all boxes

1. I confirm that I have read and understand the information sheet dated 08.05.18 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh and NHS Lothian) from the NHS organisations or other regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
4. I agree to take part in an interview and understand that audio recordings will be taken and that all information collected will be anonymised to protect my identity. ☐
5. I agree to quotations from my interview being used in publications however my data will be anonymised to protect my identity. ☐
6. I agree to my audio recorded interview being transcribed a third party contractor, 1<sup>st</sup> Class Secretarial. ☐
7. I understand that the recordings of the interview once will transcribed will be destroyed. ☐
8. I understand that my information will be stored on both an NHS computer (name and address only assigned to a study number) and on a University of Edinburgh computer (transcript) however my data will be anonymised to protect my identity. ☐
9. I agree to my anonymised data being used for future ethically approved studies. ☐
10. I agree to my GP and hospital team being informed of my participation in the study. ☐

1

Consent form date of issue: 08.05.18

Consent form version: 1.1

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London

11. I agree to take part in the above study

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person  
taking consent.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1x original into researcher site file; 1 x copy to participant

Consent form date of issue: 08.05.18  
Consent form version: 1.1  
IRAS 237440

## APPENDIX 8: CONSENT FORM FOR PARENT/ CARER NFA STUDY



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London

IRAS ID: 237440

Patient Identification Number for this study:

### Participant Consent Form

Title of Project: Parent/ carer perspective of a near fatal asthma attack

Name of Researcher: Ann McMurray

Please Initial all boxes

1. I confirm that I have read and understand the information sheet dated 08.05.18 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh and NHS Lothian) from the NHS organisations or other regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
4. I agree to take part in an interview and understand that audio recordings will be taken and that all information collected will be anonymised to protect my identity. ☐
5. I agree to quotations from my interview being used in publications however my data will be anonymised to protect my identity. ☐
6. I agree to my audio recorded interview being transcribed a third party contractor, 1<sup>st</sup> Class Secretarial. ☐
7. I understand that the recordings of the interview once will transcribed will be destroyed. ☐
8. I understand that my information will be stored on both an NHS computer (name and address only assigned to a study number) and on a University of Edinburgh computer (transcript) however my data will be anonymised to protect my identity. ☐
9. I agree to my anonymised data being used for future ethically approved studies. ☐
10. I agree to my GP and hospital team being informed of my participation in the study. ☐

1

Consent form date of issue: 08.05.18

Consent form version: 1.1

IRAS 237440



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Asthma UK Centre  
for Applied Research



Imperial College  
London

11. I agree to take part in the above study

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person  
taking consent.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1x original into researcher site file; 1 x copy to participant

Consent form date of issue: 08.05.18  
Consent form version: 1.1  
IRAS 237440

## APPENDIX 9: CONSENT FORM FOR PARENT/ CARER FA STUDY



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London

IRAS ID: 237440

Patient Identification Number for this study:

### Participant Consent Form

Title of Project: **Parent or carers perspective of a fatal asthma attack**

Name of Researcher: Ann McMurray

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 08.05.18 (version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh and NHS Lothian) from the NHS organisations or other regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
4. I agree to take part in an interview and understand that audio recordings will be taken and that all information collected will be anonymised to protect my identity. ☐
5. I agree to quotations from my interview being used in publications however my data will be anonymised to protect my identity. ☐
6. I agree to my audio recorded interview being transcribed a third party contractor, 1<sup>st</sup> Class Secretarial. ☐
7. I understand that the recordings of the interview once will transcribed will be destroyed. ☐
8. I understand that my information will be stored on both an NHS Network (name and address only assigned to a study number) and on the University of Edinburgh network (transcript) however my data will be anonymised to protect my identity. ☐
9. I agree to my anonymised data being used for future ethically approved studies. ☐
10. I agree to my GP and hospital team being informed of my participation in the study. ☐
11. I agree to take part in the above study ☐

1

Consent form date of issue: 08.05.18  
Consent form version: 1.1  
IRAS 237440



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Asthma UK Centre  
for Applied Research



Imperial College  
London

|                                   |       |           |
|-----------------------------------|-------|-----------|
| _____                             | _____ | _____     |
| Name of Participant               | Date  | Signature |
| _____                             | _____ | _____     |
| Name of person<br>taking consent. | Date  | Signature |

When completed: 1x original into researcher site file; 1 x copy to participant

Consent form date of issue: 08.05.18  
Consent form version: 1.1  
IRAS 237440



## APPENDIX 10: TOPIC GUIDE FOR BOTH NFA STUDIES



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for Applied Research



Imperial College  
London

### Topic guide for Near Fatal Asthma interviews

The interviews will be carried out with care and compassion. The interviewee or interviewer may suspend or terminate the interview at any time. If the interview is terminated by the interviewer they will explain their reasons for doing so. No explanation is required from the interviewee.

#### **Beginning the Interview**

Thank you for agreeing to meet with me to discuss your experiences. Before we start I just want to check a few things with you and make sure you are fully aware of what will happen today before I ask you to sign the consent form.

Check the following:

- Read the PIS – any questions?
- Record the interview – is this ok?
- Field notes – aware that I will be taking notes
- Reinforce confidentiality and anonymity
- Transcripts – use of quotes. Future studies.

#### **Consent**

Any questions?

- If you are happy with this, please have a read over the consent form, initial each point, and then sign it at the bottom.
- Please remember that if at any point you would like to stop the interview, or take a break you can let me know without giving any reason.

#### **Interview**

Advise that you are about to turn on the recorder.

#### *Background*

- Ask the participant to tell you about themselves and their family.
- Ask about their child's asthma – how long they have had it, what medication they are on, hospital admissions, previous asthma attacks.

#### *About the attack*

- In your own time can you tell me about the time [name of child/you] had their/ your Near Fatal attack. Start wherever you feel comfortable. If it's ok I may ask some questions when you finish.

Active listening, field notes if appropriate.

- Trigger for attack?
- Wheeze? Cough? Colour?
- Able to talk? Did they say anything?
- Medication given?
- Help called? 999?
- Thoughts at the time?
- How did it differ from previous attacks

Take a break for appropriate length of time. Stop the tape.

Restart the tape, resume interview.

Topic Guide Near Fatal Asthma  
Version 1.0 Date 19.02.18  
IRAS 237440



#### *Home environment*

- Any triggers?
- Pets?
- Smokers?
- Any stress at home or school?

#### *Other contributing factors*

We know that sometimes other factors can have an impact on asthma control, is there anything you want to discuss?

- ? family dynamics
- Mental health issues
- Other issues

#### **Ending the Interview**

- Before we finish, is there anything else you would like to add about your experiences?
- Is there anything you would like to ask me before we end the interview?

Thank the participant.

#### **Closing the Interview**

- Advise you are turning off the recorder.
- Before leaving check if they have any final questions.
- Stay with participant until any distress reduces or a family member or friend is present
- Offer details of support agencies eg Asthma UK Nurses, own clinical team.
- Offer to send a summary of findings at the end of the study – advise this may be some time in the future.

Final thanks for participation.



## APPENDIX 11: TOPIC GUIDES FOR FA STUDY



THE UNIVERSITY  
of EDINBURGH



Asthma UK Centre  
for Applied Research



Imperial College  
London

### **Topic Guide – Fatal Asthma Parent Interviews.**

The interviews will be carried out with care and compassion. The interviewee or interviewer may suspend or terminate the interview at any time. If the interview is terminated by the interviewer they will explain their reasons for doing so. No explanation is required from the interviewee.

#### **Beginning the Interview**

Thank you for agreeing to meet with me to discuss your experiences. Before we start I just want to check a few things with you and make sure you are fully aware of what will happen today before I ask you to sign the consent form.

Check the following:

- Read the PIS – any questions?
- Record the interview – is this ok?
- Field notes – aware that I will be taking notes
- Reinforce confidentiality and anonymity
- Transcripts – use of quotes. Future studies.

#### **Consent**

Any questions?

- If you are happy with this, please have a read over the consent form, initial each point, and then sign it at the bottom.
- Please remember that if at any point you would like to stop the interview, or take a break you can let me know without giving any reason.

#### **Interview**

Advise that you are about to turn on the recorder.

Ask if it is ok to use the child's name.

##### *Background*

- Ask the participant to tell you about themselves and their family.
- Ask about their child's asthma – how long they had it, what medication they were on, hospital admissions, asthma attacks.

##### *About the attack*

- In your own time can you tell me about the time [name of child] had their final attack. Start wherever you feel comfortable. If it's ok I may ask some questions when you finish.

Active listening, field notes if appropriate.

- Trigger for attack?
- Wheeze? Cough? Colour?
- Able to talk? Did they say anything?
- Medication given?
- Help called? 999?
- Thoughts at the time?

Take a break for appropriate length of time. Stop the tape.

Restart the tape, resume interview.

##### *Home environment*

- Any triggers?
- Pets?

Topic Guide Fatal Asthma  
Version 1.0 Date 19.02.18  
IRAS 237440

## APPENDIX 12: LETTER OF SUPPORT FROM LEO CAMPBELL TO THE ETHICS COMMITTEE

Dear Dr Gibson

IRAS project ID: 237440

Project title: Parent and patient perspectives of fatal and near fatal asthma, a qualitative study.

I am a lay volunteer of the Asthma UK Centre for Applied Research (AUKCAR) and during their inaugural Annual Scientific meeting I shared my personal story of bereavement. A number of years ago my 10 year old daughter died of an asthma attack. I have always been vocal about the external factors which had an impact on her death – factors which are often overlooked or not discussed. I met with Professor Steve Cunningham during that first meeting and discussed ideas for a PhD studentship.

Ann McMurray is the Chief Investigator on this study and has a wealth of experience as a paediatric asthma nurse specialist for the past 16 years. She has experience of working with parents whose children have died due to an asthma attack. She has spent time with parents working on her topic guide for the interviews which I am sure she will conduct with care and compassion.

I am aware that the Ethics Committees are there to protect participants and ensure we come to no harm by taking part in studies. As a parent who has lost a child due to asthma, I want to talk about my experience and for others to learn from me. I know other parents feel the same and actively discuss their experiences within social media and in newspaper articles. Parents will be recruited for this study from reputable organisations and make their own decision about taking part, and those who do will actively want to have the opportunity to talk about their child and their experiences which may help another family in the future.

Asthma deaths continue to occur on a daily basis and I am keen to support any research or projects which aim to reduce this from happening.

Sincerely

Leo Campbell

## APPENDIX 13: ETHICAL APPROVAL FOR QUALITATIVE INTERVIEWS

### **WoSRES** **West of Scotland Research Ethics Service**

Ms Ann McMurray  
PhD student  
NHS Lothian  
Royal Hospital for Sick Children  
9 Sciences Road  
Edinburgh  
EH9 1LF



**West of Scotland REC 3**  
Research Ethics  
Clinical Research and Development  
West Glasgow Ambulatory Care Hospital  
Dalnair Street  
Glasgow  
G3 8SJ  
(Formerly Yorkhill Childrens Hospital)

Date 22 May 2018  
Direct line 0141 232 1807  
E-mail [WoSREC3@ggc.scot.nhs.uk](mailto:WoSREC3@ggc.scot.nhs.uk)

Dear Ms McMurray

|                         |                                                                                            |
|-------------------------|--------------------------------------------------------------------------------------------|
| <b>Study title:</b>     | <b>Parent and patient perspectives of fatal and near fatal asthma, a qualitative study</b> |
| <b>REC reference:</b>   | <b>18/WS/0072</b>                                                                          |
| <b>Protocol number:</b> | <b>AC18031</b>                                                                             |
| <b>IRAS project ID:</b> | <b>237440</b>                                                                              |

Thank you for your letter of 08 May 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.



Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document                                                                                                           | Version | Date             |
|--------------------------------------------------------------------------------------------------------------------|---------|------------------|
| Copies of advertisement materials for research participants [FA ]                                                  | 1.0     | 08 May 2018      |
| Covering letter on headed paper [Ethics committee cover letter]                                                    |         | 27 March 2018    |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Insurance Confirmation] |         | 04 August 2017   |
| GP/consultant information sheets or letters [NFA Young Adult ]                                                     | 1.1     | 08 May 2018      |
| GP/consultant information sheets or letters [NFA Parent/Carer]                                                     | 1.1     | 08 May 2018      |
| GP/consultant information sheets or letters [FA Parent/Carer]                                                      | 1.1     | 08 May 2018      |
| Interview schedules or topic guides for participants [FA]                                                          | 1.0     | 19 February 2018 |
| Interview schedules or topic guides for participants [NFA ]                                                        | 1.0     | 19 February 2018 |
| IRAS Application Form [IRAS_Form_16042018]                                                                         |         | 16 April 2018    |
| Letters of invitation to participant [NFA participant invitation from hospital team version 1]                     | 1       | 20 March 2018    |
| Letters of invitation to participant [FA]                                                                          | 1.0     | 08 May 2018      |
| Other [letter to ethics committee from PPI volunteer]                                                              |         | 21 February 2018 |
| Other [Employers' Liability Insurance]                                                                             |         | 01 August 2017   |
| Other [Public Liability Confirmation]                                                                              |         | 26 July 2017     |
| Other [Clinical Trial Liability Insurance Confirmation]                                                            |         | 27 July 2017     |
| Other [Participant letter parent version 1]                                                                        | 1.0     | 20 March 2018    |
| Other [Participant thank you letter parent carer or young adult NFA]                                               | 1.0     | 20 March 2018    |
| Other [GCP Certificate]                                                                                            |         | 26 April 2017    |
| Participant consent form [NFA Young Adult ]                                                                        | 1.1     | 08 May 2018      |
| Participant consent form [NFA Parent/Carer]                                                                        | 1.1     | 08 May 2018      |
| Participant consent form [FA Parent/Carer]                                                                         | 1.1     | 08 May 2018      |
| Participant information sheet (PIS) [NFA Young Adult ]                                                             | 1.1     | 08 May 2018      |
| Participant information sheet (PIS) [NFA Parent/Carer]                                                             | 1.1     | 08 May 2018      |
| Participant information sheet (PIS) [FA Parent/Carer]                                                              | 1.1     | 08 May 2018      |
| Research protocol or project proposal [Updated Protocol]                                                           | 1.1     | 08 May 2018      |
| Response to Request for Further Information [Reply to Response to PO]                                              |         | 08 May 2018      |
| Summary CV for Chief Investigator (CI) [Ann McMurray CV 2018 - Student and CI]                                     |         | 08 May 2018      |
| Summary CV for supervisor (student research) [Louise Fleming CV]                                                   |         |                  |
| Summary CV for supervisor (student research) [Steve Cunningham CV]                                                 |         | 14 February 2018 |
| Summary CV for supervisor (student research) [Marilyn Kendall CV]                                                  |         |                  |

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

|            |                                                |
|------------|------------------------------------------------|
| 18/WS/0072 | Please quote this number on all correspondence |
|------------|------------------------------------------------|

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of  
**Mrs Rosie Rutherford**  
Chair

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

**West of Scotland REC 3**

**Attendance at Sub-Committee of the REC meeting in May 2018**

**Committee Members:**

| <i>Name</i>          | <i>Profession</i>                     | <i>Present</i> | <i>Notes</i>     |
|----------------------|---------------------------------------|----------------|------------------|
| Mrs Lorna Hammond    | Senior Clinical Pharmacist            | Yes            |                  |
| Mrs Rosie Rutherford | Volunteer - Lay Plus Member and Chair | Yes            | Chair of Meeting |

**Also in attendance:**

| <i>Name</i>                 | <i>Position (or reason for attending)</i> |
|-----------------------------|-------------------------------------------|
| Mrs Abibat Adewumi-Ogunjobi | REC Manager                               |