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**Risk factors for psychological insult following deployment to Operation  
Enduring Freedom or Operation Iraqi Freedom among veterans: A  
systematic review**

**A cross-sectional study investigating the impact of disease activity and  
disease related cognitions on adjustment in Inflammatory Bowel  
Disease**



**THE UNIVERSITY  
*of* EDINBURGH**

**Angela Seaman**

**Submitted: May 2017**

Submitted in part fulfilment of the degree of doctorate in Clinical Psychology at the  
University of Edinburgh

## DClinPsychol Declaration of Own Work

**Name:** Angela Seaman

Risk factors for psychological insult following deployment to OEF or OIF  
among veterans: A systematic review

**Title of Work:** A cross-sectional study investigating the impact of disease activity and  
disease related cognitions on adjustment in Inflammatory Bowel Disease

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# Lay Summary of Thesis

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| Degree sought:    | DClinPsychol   | No. of words in the main text of thesis: | 21447    |
| Title of thesis:  | 1) Risk factors for psychological insult following deployment to Operation Enduring Freedom or Operation Iraqi Freedom among veterans: A systematic review<br><br>2) A cross-sectional study investigating the impact of disease-activity and disease related cognitions on adjustment in Inflammatory Bowel Disease |  |          |

Insert the lay summary text here - the space will expand as you type.

1)Veterans may be vulnerable to certain mental health problems like anxiety, depression, and Post Traumatic Stress Disorder (PTSD). However, getting accurate information on the numbers of people who may be more susceptible is quite difficult because veterans may not want to disclose what they are experiencing. There are certain types of veterans that may be at increased risk of mental health problems relating to their occupation, if they were a regular or reserve and their circumstances prior to joining the armed forces. For these reasons, veterans may need specific support to meet their unique needs and the aim of this systematic review was to get a clearer idea of the types of veterans that may be more vulnerable to mental health problems to target these needs better.

Five research databases were searched which identified 278 records that assessed the risks to veterans. After going through these, 10 papers were eventually selected based on pre-determined criteria. The excluded papers spoke about related topics but did not specifically look at the risks for veterans of mental health problems. The final 10 papers were compared and appraised against a set of criteria that were designed to answer the research question.

All of the 10 studies identified risk factors although because all the papers used different methods and types of veterans it was difficult to compare them. However, one finding that did come up consistently was that combat exposure and being deployed seemed to be linked to mental health problems once they returned from duty. This provides some evidence that there are specific risk factors that may increase risk to mental health problems in veterans. Therefore, veterans would benefit from support that looks at these

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## Lay Summary of Thesis

risk factors and helps to increase those things that may be protective for veterans such as social support.

2) Adjustment to receiving a diagnosis to Inflammatory Bowel Disease (IBD) can be a very challenging time but also provide long awaited answers. The purpose of this research was to investigate this adjustment further in order to see if psychological support may be helpful at this stage to facilitate people to come to terms with diagnosis. We know already that IBD can cause a lot of distress, which in turn can have a negative effect on Quality of Life (QoL) and this is more likely to be the case if the IBD is currently active or one has just been diagnosed. So this study was keen to look at the things that help one to adjust to receiving a diagnosis of IBD.

The majority of the participants that agreed to take part saw the research on the Chron's and Colitis Facebook page where we put the advert. The questionnaire was self-report, meaning that it was based on individuals' answers to the questions. The 12 questionnaires used had already been developed for people with IBD and were chosen to give a clear picture of the whole profile of IBD, such as, psychological factors, QoL and adjustment to diagnosis. In total 338 people responded to the questionnaire.

What we found was that adjustment to receiving a diagnosis, QoL and psychological functioning were all linked in some way. In addition, adjustment to diagnosis had an effect on levels of stress, depression and anxiety, which is a really important finding. We also found that the longer someone has a diagnosis, the more they will get used and adapt their lifestyle to accommodate it to be able to do more of the things they want like taking part in activities. Therefore, there are a number of things that can increase risk of having a poorer QoL and increase psychological distress such as how active your disease is, how much you think IBD affects you, how you think about pain and if you feel stigmatised. We hope that they will give people more information to be able to develop psychological help so that people with IBD get the support they need.

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## **Acknowledgements**

Firstly, I would like to thank all the individuals who participated in my research as without them this would not have been possible. Thank you to Crohn's and Colitis (C&C) UK for agreeing to post my research on your website and social media, and especially so to the C&C Clyde group, who gave me lots of ideas and inspiration when I met with them. I hope that the findings of this research will inform future psychological interventions and facilitate individuals to access the support they need.

I would like to thank Dr Nuno Ferreria, my academic supervisor for his support and advice throughout the project and Dr Bruce Downey, my clinical supervisor for stepping in during the late stages of my thesis and providing feedback on my drafts. I would also like to thank Dr Lucy Abrahm at Veterans' First Point who helped me during the early stages of my thesis.

Special thanks go to my parents as without them none of this would have been possible. Their support and has been invaluable. And to David, a huge thanks goes to you for being patient and understanding with me. Last but not least to Jocelyn who has been a continual reminder of what is important in life.

## **Contents**

**Chapter 1:** Systematic review and research journal abstract

**Chapter 2:** Systematic review

**Chapter 3:** Empirical research journal article

**Word count for main body of thesis:** 21447 (not to exceed 30, 000)

## **Chapter 1**

### **Systematic review and research journal abstract**

#### **Risk factors for psychological insult following deployment to Operation Enduring Freedom or Operation Iraqi Freedom among veterans: A systematic review**

**The systematic review** aimed to establish more clearly the risk factors for mental health problems in the veteran population. Five databases were searched. Included studies (n = 10) required that veterans served in Operation Enduring Freedom (OEF) and/ or Operation Iraqi Freedom (OIF) and included risk factors of mental health problems among the veteran population. Data from included studies were extracted and critically appraised based on critical appraisal tools following a narrative approach to synthesise data. All of the studies reviewed identified risk factors, although due to their heterogeneous nature key findings varied considerably. However, it was consistently reported that combat exposure and deployment experiences were associated with emergence of post operational mental health problems. The current review provides preliminary evidence that there are a number of specific risk factors that may increase susceptibility to mental health problems subsequent to military deployment. It is suggested that interventions are needed in order to mitigate risk factors and bolster protective factors.

#### **A cross-sectional study investigating the impact of disease activity and disease related cognitions on adjustment in Inflammatory Bowel Disease**

**The research journal** aimed to investigate the degree to which psychological illness related cognitions will mediate the effect of disease activity on Quality of Life (QoL). In addition, to assess the impact of disease activity, and several psychological factors, in several adjustments outcomes in IBD to see whether the adjustment variables are significant predictors of multiple outcomes. Mediation was used followed by an exploratory cross-sectional correlational design. Three hundred and thirty eight participants were recruited through an IBD charity and invited to respond to a self-report questionnaire online. Measures targeted different aspects of the IBD profile

to give an indication of adjustment associated with IBD diagnosis, psychological factors and Quality of Life (QoL). Mediation analysis found support for significant indirect effects on the relationship between disease activity and QoL through Gastrointestinal (GI) anxiety, perceived disability and illness representations. The subsidiary analysis indicated that pain catastrophising, disease activity, stigma, illness representations and GI anxiety were found to be significant predictors of adjustment in IBD. The results indicate that there is an important relationship with the adjustment factors, QoL, and psychological functioning. In addition, stress, depression, anxiety and QoL were found to be predicted by the adjustment factors. The current study has provided insight into psychological factors and adjustment indicators from a multi-faceted perspective, which will facilitate advancement of managing IBD from a biopsychosocial framework with a view to enable more effective disease management.

**Risk factors for psychological insult following deployment to Operation  
Enduring Freedom or Operation Iraqi Freedom among veterans: A  
systematic review**



THE UNIVERSITY  
*of* EDINBURGH

**Submitted:** May 2017

**Journal Format:** Military Behavioural Health

The journal's author guidelines for structure, style and referencing have been followed and can be found in *Appendix 1*. Adaptations have been made for coursework submission guidelines

Submitted in part fulfilment of the degree of doctorate in Clinical Psychology at the University of Edinburgh

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**Declaration of Interest:** None

**Word Count:** Abstract: 250 words; Main Report: 9653 words

## **Abstract**

**Background** The overall proportion of veterans with mental health problems in the UK is relatively small compared to the civilian population, with the most prevalent concerns being depression and anxiety (Iversen et al., 2009; Murphey et al., 2008). Veterans continue to pose significant challenges to mental health care provision because of their occupation and the unique hazards associated with this role, mobility issues and stigma associated with mental health needs (Pinder, 2010). Knowledge of vulnerabilities and risk factors may lead to increased understanding of this population and how to better address veterans' needs.

**Objectives** The aim of this systematic review was to establish more clearly the risk factors for mental health problems in the veteran population.

**Method** Five databases were searched. Included studies (n = 10) required that veterans served in Operation Enduring Freedom (OEF) and/ or Operation Iraqi Freedom (OIF) and included risk factors of mental health problems among the veteran population. Data from these studies were extracted and critically appraised based on critical appraisal tools following a narrative approach to synthesise data.

**Results** All of the studies reviewed identified risk factors, although due to their heterogeneous nature key findings varied considerably. However, it was consistently reported that combat exposure and particular deployment experiences were associated with emergence of post deployment mental health problems.

**Conclusions** The current review provides preliminary evidence that there are a number of specific risk factors that may increase susceptibility to mental health problems in veterans post deployment. It is suggested that interventions are needed in order to mitigate the risk factors and bolster protective factors.

## **Keywords**

Risk factors, vulnerability, mental health, PTSD, veterans, post deployment, regular, reserve, OEF, OIF

## **1.2. Introduction**

In the United Kingdom (UK), a veteran is defined as a person who has served at least one day in the military, either as a deployed soldier or deployed reservist (Dandeker et al., 2006).

Operation Enduring Freedom (OEF) and Operation Iraq Freedom (OIF) were the two most recent and sustained military campaigns led by the US since the Vietnam War. OIE ('The War on Afghanistan') was a sustained combat following the 2003 US invasion of Afghanistan, the public aims of which were to remove the Taliban from power in the 'war against terror'. OIF was the armed conflict that begun in 2003 with the invasion of Iraq by a US led coalition that toppled the government of Saddam Hussein which was a suspected threat of weapons of mass destruction.

Although deployed personnel are likely face a plethora of stressors identified and studied in veterans of past conflicts including, fear for own life and participation in killing, evidence suggests those who served in OIE and OIF will also face new challenges (Hoge et al., 2004). Deployed personnel to OIE and OIF are likely to have experienced more intense combat experiences compared to other war fighting periods and more frequent and intense involvement in combat operations, which has the potential to increase risk of developing PTSD symptoms and mental health problems (Hoge et al., 2004). According to Hoge and colleague's (2004) study, these may include receiving small-arms fire, knowing someone who was seriously injured or killed, seeing dead or seriously injured soldiers, and handling or uncovering human remains. Moreover, the majority of soldiers deployed to Iraq reported shooting or directing fire at the enemy and about a half reported being responsible for the death of an enemy combatant (Hoge et al., 2002).

In addition to more intense combat experiences, a set of unique stressors come from the fact that the conflict in Afghanistan and Iraq has been characterised by guerrilla warfare and terrorist actions from unknown civilian sources. In this context, military personnel are required to sustain high levels of vigilance and sensitivity to threats at

all times, whilst being aware of the danger of collateral damage to civilians in urban areas. There may also be a range of specific environmental stressors and dangers associated with being posted to OIE and OIF, such as, poor diet, severe weather and deficient accommodation which are likely to influence response to deployment (Hoge et al., 2002). There remains uncertainty regarding adjustment to the requirements of these new types of war zones, which none the less are essential to identify the needs of the newest veterans accessing services following serving in these operations.

### **What are the presenting psychological issues of veterans?**

There is a considerable body of research indicating the overall proportion of veterans with mental health problems in the UK is relatively small compared to the civilian population, with the most prevalent concerns being depression, anxiety, and alcohol misuse (Iversen et al., 2009; Murphey et al., 2008). However, in the UK mental health problems among deployed personnel seems to remain comparable to the general population with prevalence being 19.6% (Fear et al., 2010). Perhaps surprisingly, it is consistently reported across studies that rates of Post Traumatic Stress Disorder (PTSD) represent the lowest proportion of veteran presentations (Helzer et al., 1987). However, it is widely acknowledged that obtaining an accurate estimate of prevalence of psychological problems in the veteran population is complicated by stigma (and associated underreporting) and reluctance amongst this population to access mental health services (Hoge et al., 2004; Pietrzak et al., 2009). In 2014, 57.2% (622,722) of veterans registered with Veterans Affairs (VA) healthcare in the US received a provisional mental health diagnosis, with the most common being PTSD (55%). This represents an increase of 76% since 2008 (Kehle et al., 2011).

The history of PTSD frequently references combat experience as it is widely accepted that military combat involves exposure to traumatic experiences, giving rise to trauma conditions (Goldberg et al., 1990). However, it was only in 1980 that the APA included PTSD to DSM-III following research with returning Vietnam War Veterans which made the association between exposure to war trauma and adjustment to

civilian life (3rd ed.; Diagnostic and Statistical Manual of Mental Disorders; American Psychiatric Association, 1980). PTSD is now characterised by reliving symptoms, avoidance, hyperarousal and changes in beliefs and feelings (emotional numbing) following exposure to an event(s) involving threat to life which elicited feelings of helplessness, fear and/ or horror (Gates and Holowka, 2012). In general it is widely accepted that the greater degree of combat exposure, the greater the chance of emerging PTSD and longer symptom duration (Hoge et al., 2004). There is some evidence suggesting that men who state combat trauma is the most traumatic event in their lives are seven times more likely to develop PTSD than those who do not (Prigerson et al., 2001). Combat associated PTSD specifically has also been shown to be associated with lost work productivity and marital discord (Prigerson et al., 2002) as well as some physical problems (Hoge et al., 2004). However, it is important to note that not all individuals exposed to traumatic events go on to develop a psychiatric disorder, and this may depend on the intensity of the traumatic event as well as a range of pre and post trauma related influences (Norris et al., 2002).

### **Risk factors for psychological distress**

#### ***Occupational risk factors specific to military and veteran populations***

Certain types of veterans including Early Service Leavers (ESL's; less than four years service; British Army, 2009), those with physical health disabilities and reservists may be at increased risk of having poorer mental health outcomes than others (Iversen et al., 2009). Risk was also found to be higher in those UK veterans who served in the army, who were employed at a lower rank, who were single (Iversen, 2005), and among those who experienced pre-enlistment or childhood adversity (Cabrera, 2007; Iversen, 2007).

A number of proxy markers, such as type of service, may play an important role in moderating risk of mental health problems among military personnel (Solomon et al., 1994). Greenberg and colleagues (2012) found deployment to a combat area or operation was associated with increased risk of mental health problems (including PTSD) and poorer physical health outcomes. Occupational factors that could be

modified, including unit morale, leadership and preparedness for a specific role in the military theatre, have further been shown to influence the likelihood of developing a mental health problem (Iversen et al., 2008).

### ***Reserve veteran populations***

Reserves that have been deployed to a combat area or operation have been shown to have an increased prevalence of mental health problems and fatigue compared to regular veterans (Hotopf et al., 2006). In a study looking at reserves deployed to Iraq, they were shown to have less-transient and more chronic problems, and be at higher risk of PTSD and relationship difficulties up to five years after their tour of duty (Greenberg et al., 2012). This may be due to reserves having to adapt more quickly to military factors, for example, roles in theatre, team cohesion, and exposure on tour, which may make them more susceptible to mental health issues than regular personnel (Browne et al., 2007). Therefore, as well as deployment experience and exposure, less time to prepare may also be a potential factor in increasing vulnerability to mental health problems.

Reserves report greater concern about risk to life than regular veterans (Hotopf et al., 2006) and have more worry about families not having access to adequate welfare services during deployment (Eversden-French, 2007). Less perceived security whilst on deployment may be influenced by a multitude of factors, for example, own perceived lack of experience, less well formed relationships within a deployed unit, feeling of lack of preparedness, knowledge of family support (or lack thereof) and among previously injured reservists.

Transition to civilian life for reserves may also, in part, account for increased mental health problems, due to a lack of post-deployment support (Iversen and Greenberg, 2009). For example, at the end of Operation Telic 1 (the main active combat period that commenced with the invasion of Iraq in May 2003), reserves were dispersed immediately following return from duty. Moreover, reserves in subsequent deployments have also faced a plethora of additional difficulties associated with the decline in popularity and support from society for such operations; a factor that may

have contributed to the increased risk of psychological distress in veterans following the Vietnam War (Marlowe, 2000).

### ***Socio-economic risk factors***

Specific subgroups of the armed forces may be at increased risk of mental health problems. Therefore, better understanding of premorbid functioning or dynamics that might indicate psychological vulnerability is essential from an early intervention point of view. Ismail (2006), for example, found that Gulf war veterans were twice as likely to report mental health problems if they were divorced, separated or widowed when compared to those who were married or co-habiting. In a study conducted by Jones et al. (2012), increased susceptibility to PTSD was associated with those from lower ranks, with those that had experienced childhood adversity and/ or serious accidents, and ESL's. These factors were found to be at least as significant as holding a combat role.

According to Woodhead et al. (2011), veterans who experience mental health problems are more likely to experience some degree of impairment in social or occupational functioning than those who do not. Importantly, this may adversely impact upon areas such as employment (Iversen et al., 2005b), relationships, marital satisfaction and family stability (Taft et al., 2008).

Alcohol misuse among the veteran population represents an increasing concern (Dandeker, 2003; Iversen et al., 2005). To date the evidence is unclear if veterans use alcohol as a coping mechanism to deal with mental health symptoms. In a US study conducted by Bray and colleagues (1995) only one in seven personnel was receiving treatment for alcohol misuse, despite personnel recognising the importance of specific services for this. Alcohol misuse among veterans has also been associated with homelessness (Dandeker, 2003). In a random sample from the King's Military cohort (Hotopf et al., 2007), heavy drinking (more than 30 units per week) was more prevalent in those that were unmarried or separated, and had poorer perception of their physical and mental health needs. However, it is difficult to draw meaningful conclusions from this sample, as no direct comparison group was available.

Social exclusion within the first year post-discharge is a considerable issue among ex-service personnel and may increase the risk of becoming homeless. Risk factors for homelessness among veterans are likely to vary compared to the civilian population. For example, veterans tend to be older, and have greater levels of alcohol dependence and physical health problems compared to the general population (Dandeker, 2003). Other risk factors of becoming homeless include relationship breakdown and unemployment (Dandeker, 2003). Incidentally, data on employment rates among veterans is somewhat sparse, although some evidence indicates rates of unemployment are high (Dandeker, 2003). What does exist seems to be biased towards those who are employed, and therefore underestimates unemployment due to difficulties in sampling and recruitment.

Post deployment mental health problems are clearly associated with a range of social and behavioural factors, including alcohol misuse, homelessness and consequential impact such as increased likelihood of involvement in violence. Consequently, need is firmly established, with support services to meet need clearly required. Despite this, only 36% of 52 veterans interviewed were aware of support services providing social-welfare support in a study conducted by Dandeker (2003). One of the recommendations from this study was delivery of services across the public sector needs to be more co-ordinated, integrated and responsive to the needs of the veteran population.

### ***Method and rank at discharge***

At present the UK Army routinely deploys personnel in accordance with the 'Land Harmony Guidelines', which amounts to deployment for six months at a time or no more than 12 months in any given 36-month time frame (Rona et al., 2007). In a systematic review of nine studies by Buckman and colleagues (2010), seven studies found that greater length of deployment had a negative impact on health and wellbeing outcomes; especially if deployment lasted longer than expected.

Fear and colleagues (2009) found that low rank, poor perceived job control, and high demand were associated with PTSD, increased psychological distress, and negative physical health symptoms and fatigue. It was noted, however, that social support in general may provide a buffering effect. Somewhat related, Ismail (2006) suggests that military rank in Gulf veterans moderated propensity to mental health problems. However, Fear and colleagues (2009) found that when rank was adjusted for in their analysis it did not have an additive effect on the association between job strain and mental health problems. Noting how individuals who held high strain jobs were more often from lower socioeconomic backgrounds and typically had lower levels of educational attainment, the authors concluded that this group may have been more susceptible to experiencing mental health problems prior to armed forces service.

Meanwhile, Buckman and colleagues (2011) described how military discharge, rather than operational service, appears to be a key predictor of both physical and mental health problems (including PTSD) in veterans; especially among ESL's. Hatch and colleagues (2013) suggest that this increased risk may be accounted for, in part, by service leavers having fewer social networks in their civilian lives. Perhaps in-keeping, Hoge (2002) noted that those with pre-existing mental health problems are more likely to be ESL's, while Rosenheck (1994) highlighted increased risk of social exclusion in this group. Increased vulnerability of ESL's may be compounded by the mere fact they are an ESL, which in itself suggests discharge for medical, administrative or disciplinary reasons.

### **Barriers to help seeking among veterans**

Once UK military personnel leave the Armed Forces the responsibility for their health care rests with the National Health Service (NHS). However, there is a considerable body of research suggesting that veterans are reluctant to access support for mental health problems (Iversen et al., 2010; 2011). Veterans who experience mental health problems often highlight barriers to accessing care and concerns about potential stigmatisation, to a greater degree than practical or logistical barriers (Hoge, 2004), consistent with civilian literature regarding avoiding public stigma (Ben-Zeev et al.,

2012; Greene-Shortridge et al., 2007). Hoge and colleagues (2004) found veterans with anxiety and/ or depression were more likely to report stigmatizing beliefs when compared to veterans without symptoms of such a mood disorder. This may be due to a combination of factors, including unwillingness to discuss mental health problems or a lack of sufficient services to meet veterans' particular needs. However, it is worth noting that a similar percentage of civilians were also not receiving treatment. Stigma within the armed forces (and subsequent under reporting of mental health problems) has been associated with a range of perceived desirable characteristics in the military, including toughness, self-sufficiency and focus on military preparedness (Dunt, 2009) which may go some way to explain why military personnel may see help-seeking as a sign of weakness and express concerns around differential treatment and loss of trust from ones unit.

The social-cognitive model postulates that stigma is a complex phenomenon that transpires as a result of stereotypes, prejudice and discrimination following identifying and subsequently labelling difference, for instance, within certain groups (Link and Phelan, 2001). In mental illness, social and cultural or environmental cues may facilitate the social-cognitive process of stigmatisation through identifying difference. This may exasperate so called 'label avoidance' regarding diagnosis which has been shown to lead to reduced engagement with services (Ben-Zeeve et al., 2012) due to concern accessing support will invoke stigma. The experience of stigma can have huge ramifications on individuals, including on their ability to help-see. As such, military personnel may experience self-stigma, whereby public stereotypes about being in the military and experiencing mental health problems are internalised and integrated to form part of self-concept (Muñoz et al., 2011). This can subsequently impact on self-esteem and bring about feelings of shame (Rüsch et al., 2014). Double stigma may also occur in groups of individuals who are associated with a number of socially disadvantaged groups. For example, Foynes and colleagues found that US marines who are subjected to racial discrimination during service were more at risk of developing mental health problems.

Literature on non-disclosure among military personnel suggests that military culture may encourage individuals to resolve their own problems due to fear of structural stigmatisation within the military (Greene-Shortridge et al., 2007). Thus, organisational discrimination within the military can potentially lead to internalised stigma beliefs, such as, “I am weak” or “I am crazy” (Pury et al., 2014). Unit leadership, as well as individual beliefs about stigma, have consistently been found to impact likelihood of accessing support and sharing experience of mental health problems. Stecker and colleagues (2007) found that leadership in the military may discourage reporting of symptoms due to concerns of the long term ramifications of being associated with a particular problem, although higher unit-cohesion can mitigate this and reduce stigma. Veterans in particular may have concerns that professionals outside the military may not fully comprehend the context of their experience.

Courtesy stigma (Goffman, 1963) refers to stigma experienced as a result of association with the stigmatised individual, including employers as well as outside agencies who are connected with the military as well as members of the public. In a systematic review by Coleman and colleagues (2017), they found military personnel may experience worries that seeking help would negatively impact on their career progression and possibly result in discharge or a change in duties. Military personnel also expressed concerns that confidentiality could be breached if they were seen to take time off to attend appointments (which would be difficult to conceal among ones unit) as other unit members would infer they were getting treatment for mental health problems. Higher-ranked officers were particularly concerned about losing power, whereas lower-ranked officers were predominantly concerned with a reduction in deployment opportunity. Courtesy stigma therefore has the effect of excluding and giving social space between those in direct contact with the individual and stigmatised person as a means of avoidance (Pryor et al., 2012).

Perhaps reflective of these issues, Iversen and colleagues (2005) found approximately half of veterans with a pre-existing diagnosis seek help. Within this context, there is increasing recognition of the importance of cultural shift acting as a

catalyst to challenging barriers to help seeking among personnel; with the military peer-led stress management system (an embedded service that does not rely on help seeking from outside ones command) providing a good example of an initiative aimed at reducing mental health stigma (Gould, 2007).

Van Hoorn and colleagues (2013) analysed the records of veterans that presented to the Combat Stress service between 2003 and 2011, and whom had served in operational duties in Iraq and Afghanistan. Of 988 veterans, the majority sought help after two post-operational years had elapsed. The majority seeking help were also around ten years younger than veterans who served in other operations. This represents a shift in help seeking and may reflect recent efforts to de-stigmatise mental health during these campaigns, and because of Combat Stress' advertising and self-referral process (Greenberg et al., 2011), as well as increased knowledge of risk factors. It is of interest that only 5% of the sample had been referred by their General Practitioner (GP). This suggests that veterans may not want to disclose their mental health needs to their GP, or that GP's may not be aware of veterans services or what veteran specific information to ask about during the assessment process (Greenberg et al., 2011).

### **Support services for veterans**

Veterans continue to pose significant challenges to mental health care provision because of their occupation and the unique hazards with this role, mobility issues, and stigma associated with mental health needs (Pinder, 2010). In recognition of the unique risk factors associated with mental health problems among veterans, specific services designed to meet their particular set of needs have begun to be developed. Largely influenced by increased awareness of the psychological burden placed on the UK Armed Forces, particularly highlighted by the recent conflicts in Iraq and Afghanistan (King, 2009), a number of pre-existing UK charitable organisations for veterans have responded to need by developing new services that offer veterans much needed mental health support. The services offered by Combat Stress provide one example of such an initiative. As well as this, NHS funded initiatives specific for

military personnel, such as veterans 'Improved Access to Psychological Therapies' (IAPT) and Veterans First Point (V1P) have also been developed. Although it is noted that there is significant variation in the choice of model of service delivery used by each regional NHS veteran service, the fundamental aims are the same; to ensure gaps in service provision are filled and joined up working is more effective. Other organisations currently providing advice and welfare support to veterans living in Scotland include the National Armed Forces Charity (formerly the Soldiers, Sailors, Airmen and Families Association, SSAFA), Poppy Scotland, Erskine, The Royal British Legion (Scotland), and the Service Personnel and Veterans Agency (SPVA). Veterans Scotland is the umbrella organisation for all veterans' charities in Scotland.

### **1.3. Aim**

This systematic review aims to answer the following research question:

What are the risk factors for mental health problems in the veteran population following deployment to sites covered during Operation Enduring Freedom (OEF) or Operation Iraqi Freedom (OIF)?

In order to answer this question, information on a range of demographic and psychosocial variables will be collected and considered in relation to their potential utility in predicting subsequent risk to mental health. In particular, information relating to deployment and combat experience (and/ or exposure), pre-enlistment vulnerability factors, such as educational attainment, socio-economic status, history of childhood adversity, pre-enlistment mental and physical health status, level of social support both pre-and post-deployment, and transition to civilian life post-deployment. The above factors were selected as the existing literature base suggests a relationship exists between such variables and development of mental health problems in veterans.

It is anticipated that findings from the review will further enable risk factors to be addressed and barriers to help seeking overcome through a tailoring of support services to meet the specific needs of this population.

## **1.4. Methods**

### ***Search strategy***

A search was carried out in June 2016 using the following databases: PsycINFO (1987 to June week 3 2016); Embase Classic + Embase (1947 to 2016 June 19); Ovid MEDLINE® (1946 to June Week 2 2016); ASSIA (1987 – current); Social Services Abstracts (1979 – current); ProQuest Dissertations and Theses Global; CINAHL; Web of Science; Opengrey.eu; Cochrane Trials Library. Only articles after 2001 were selected to cover the time period of Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF). Search terms, which were chosen for being broad and achieving the highest number of articles during initial scoping searches, were used consistently with every database. Searches were not confined to a specific aspect of any research paper. The search terminology used was: (“risk\*” OR vulnerabl\* OR impact OR help-seeking OR adjustment OR resilient\*) AND (“mental\*” OR psychiat\* OR psycholog\* OR self-harm OR suicide OR anxiety OR depression OR post traumatic stress\* OR PTSD OR welfare\* OR well-being OR physical\* OR social\*) AND (“veteran\*” OR post military\* OR post deployment OR military veteran\* OR regular OR reserv\* OR ex-military OR ex-service OR early service leave\* OR ESL or ex-armed forces OR military veteran). Further studies (n = 2) were identified by checking the reference list from identified studies, and more were obtained from veteran organisations websites (n = 7) (for example, Kings Centre for Military Health Research and Academic Centre for Defence Mental Health publications, V1P, and charitable organisations such as Veterans UK, Army Welfare Service, Veterans Scotland, Poppy Scotland, SSAFA, Combat Stress and Legion Scotland).

### ***Inclusion criteria***

- Studies relating to military involvement during the time period of OEF (October 2001 – December 2014) and/ or OIF (March 2003 – August 2010);
- Articles clearly specifying that the study population were veterans, regardless of combat role, rank, deployment, and length of deployment. This included

- regular, reserves and ESL's with or without a current physical or mental health diagnosis;
- Primary studies- inclusion of risk factors for mental health problems among the veteran population. This encompassed psychological, social, demographic and biological risk factors;
  - Grey literature and unpublished studies were included in order to broaden the scope of results and encompass a more complete view of available evidence;
  - Intervention studies were included if they focussed exclusively on specific risk factors associated with deployment during the period OEF or OIF;
  - Studies conducted in any setting, including non-clinical settings, and across all formats (for example, online, telephone, face-to-face) were included.

#### ***Exclusion criteria***

- Articles not clearly addressing risk factors and their relation to mental health problems among veterans (so excluding allied health professionals, diplomatic staff, prisoners of war, peacekeepers, security industry contractors, and effects on military children or at-home spouses/ caregivers, as well as protective factors);
- Studies focussing on populations other than veterans;
- Studies describing risk of physical health problems in veterans (pre-enlist or post-service), utilisation of health care or stigma and service use/ barriers to help seeking (unless specifically mentioning risk factors);
- Individual case studies, small n designs, reviews and intervention studies or studies looking at assessment and treatment needs of veterans;
- Studies focussing on investigating factors specifically relating to men or women separately;
- Due to resource limitations, this review only included English language studies.

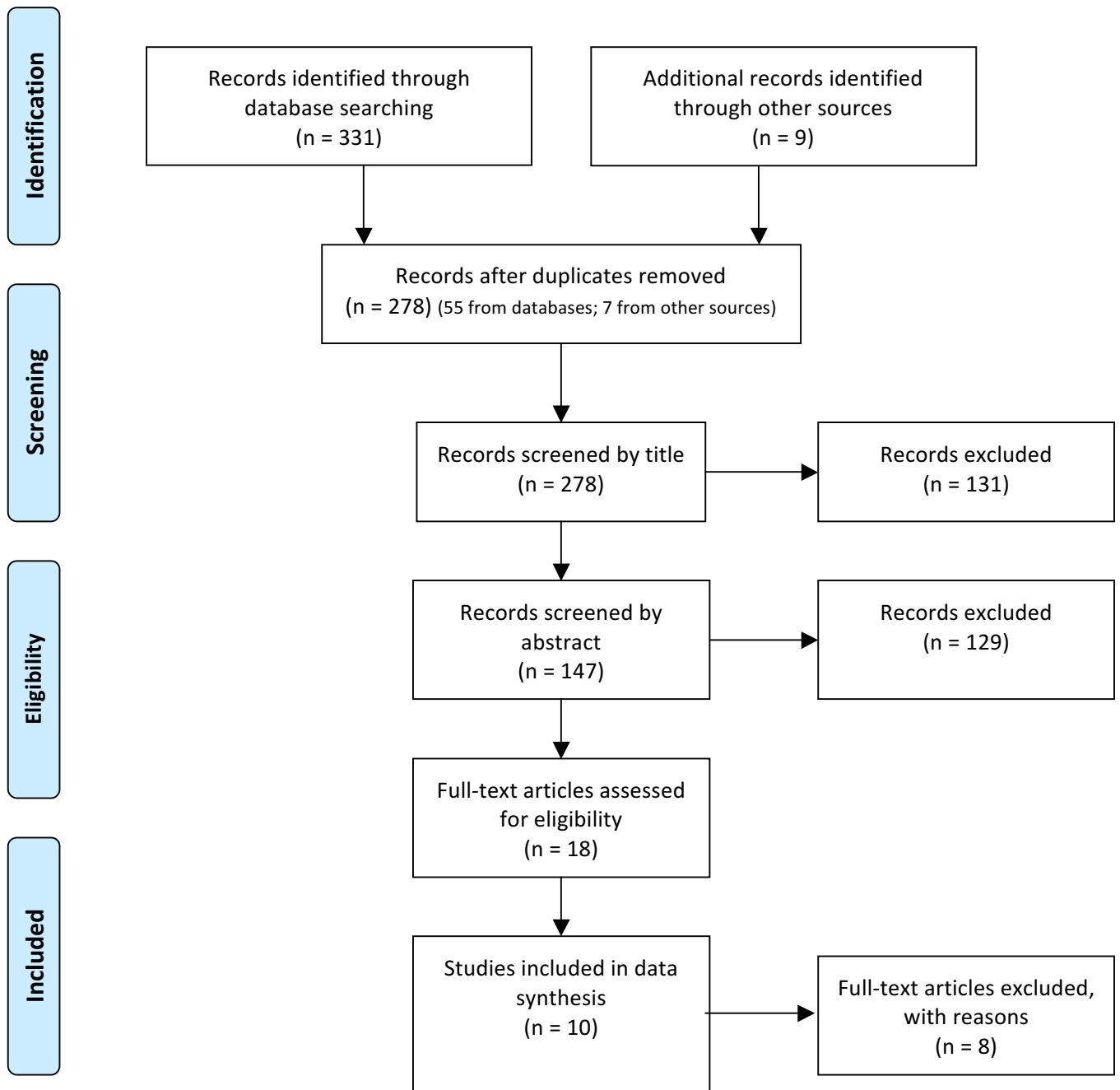
#### **1.5. Results**

A search of the Cochrane library of systematic reviews using the search terms listed above found that no reviews similar to the one proposed have been published to date.

### ***Characteristics of included studies***

The search yielded 340 publications: 75 from PsycINFO, Embase Classic + Embase and Ovid MEDLINE®; 19 from ASSIA, Social Services Abstracts and ProQuest Dissertations and Theses Global; 37 from CINAHL; 167 from Web of Science; none from Opengrey.eu; 33 from the Cochrane Trials Library and nine from other sources. This was reduced to 278 after removing duplicates. The titles and abstracts from the identified articles were checked for relevance against the inclusion criteria, which resulted in the identification of 147 articles. Of these, 129 were excluded as they did not meet the inclusion criteria. Remaining articles were screened in full (n = 18), of which eight did not meet the criteria. Where there was uncertainty about whether to include a study based on the abstract, the full article was checked. Reference lists of all the studies that met the inclusion criteria were screened to check for any additional studies that could be included. Articles were assessed for suitability by two independent raters (P.R and R.S), and any differences were resolved following discussions. Ten articles were deemed suitable for inclusion (see *Figure 1*).

**Figure 1: Literature search flowchart**



Adapted from PRISMA flowchart (Moher et al., 2009), showing numbers of articles at each stage in the process of selecting studies for inclusion.

The greatest number of articles were excluded from screening the title (n = 131) on the grounds that they (a) were not related directly to veterans (for instance, they were about caregivers), (b) addressed physical health problems in veterans, (c) considered pre-enlistment physical health and increased mental health risk post-deployment, (d) looked at stigma and service use specifically or help-seeking and utilisation of health care.

Eight studies were excluded in total. Two because they focussed on a military cohort of veterans who did not serve in OIE and/ or OIF (Ismail et al., 2000; Wessely, 2007). A further two studies were review studies. Ramchand and colleagues (2015) looked at the epidemiology of PTSD and mental health problems in those returning from OIE and OIF. Walker (2010) conducted a systematic review to assess how a military career affects the mental health of veterans. One study examined resilience and protective factors (Elsen et al, 2015), whereas Polusny and colleagues (2011) focussed specifically on the impact of prior deployments on mental health in national guards and reserves one month prior to deployment to OIF. Erbes and colleagues (2011) looked at occupational functioning and how this may be affected by mental health problems, and Kar and O’Leary (2013) assessed the relationship between PTSD and physical intimate partner violence.

Summary information for each article was identified and is presented in *Table 1*. This included, for example, the study aim, design, sample characteristics, outcome measures, analysis, identified risk factors and main conclusions. Attempts were made to contact authors to obtain potentially relevant data not provided in their publications. Due to the variety and diversity of the included studies, they do not enable outcomes to be reliably compared across studies. Therefore, the summary must be interpreted with caution.

**Table 1: Description of studies included**

| Study reference/<br>Country       | Aim   | Mental health focus | Design   | Outcome measures                       | Population (role, N, age, gender, other)  | Inclusion & Exclusion criteria   | Analysis  | Main risk factor(s) identified/ Results   | How findings relate to review aim  |
|-----------------------------------|---|---------------------|--|--|---|--|---|---|--|
| Booth-Kewley et al. (2013)<br>USA | Identify factors affecting incidence of new-onset psychiatric disorders | General MH          | Prospective, longitudinal one year follow-up via self-report surveys & military record databases | CHAMPS, DMDC, Warfighter Status Survey | US Marine Corps<br>N= 1113,<br>39.2% between 22-26 years,<br>96% M                  | Exc- previous psychiatric diagnosis/ reservists<br>Inc- active duty in previous deployments                  | Univariate & multivariate logistic regression       | Female gender/ mild TBI<br><br>Satisfaction with leadership & high organisational commitment reduces risk (OR = 1.85, p<0.01 and OR = 0.62, p<0.05) | Deployment is a risk factor for new-onset psychiatric disorder                   |
| Seal et al. (2009)<br>USA         | Identify high-risk subgroups to develop MH services within the VA       | General MH          | Longitudinal study. Review of VA medical records   | Veterans enrolled in VA Health Care    | N= 289328<br>F= 21407 (12.6%)<br>M= 147998 (87.3%)<br>25-29 years, N= 56488 (33.3%) | OIF & OEF veterans who were 1 <sup>st</sup> time users of VA healthcare after their military service between | Cumulative prevalence, negative log-binomial models | 106728 (36.9%) received diagnosis, 62929 (21.8%) with PTSD, 50432 (17.4%) with depression.<br>Risk factors include                                  | Several identified risk factors for receiving a diagnosis among specific veteran |

|  |  |                                     |   |   |  |  |                        |  |   |
|--|--|-------------------------------------|---|---|--|--|------------------------|--|---|
|  |  |                                     |   |   |  | 2002-2008/<br>active duty,<br>national guard<br>& reserves   |                        | active duty, less 25<br>years old, combat<br>exposure (RR = 2.0<br>compared with 4.9<br>for over 40 years<br>old). Women<br>greater risk<br>depression, men<br>drug use disorders  | subgroups.<br>MH diagnosis<br>is increasing<br>among VA<br>veterans   |
| Schultz et<br>al. (2014)<br><i>USA</i> | Identify<br>predictors of<br>worsening MH<br>over a 6-<br>month period<br>following<br>return from<br>deployment | General MH,<br>PTSD,<br>alcohol use | Observational.<br>Survey- within<br>2 months<br>from return at<br>T1 & T2 (6<br>months later) | DRRI, Bartone<br>Hardiness<br>Scale, General<br>Self-Efficacy<br>Scale, PCL-M,<br>Veterans<br>RAND Short<br>Form, AUDIT-<br>C | N= 512, F= 306<br>(59.8%), M= 206<br>(40.2%), number<br>of 35-44 years=<br>162 (31.6%) | Women<br>oversampled to<br>comprise 50%.<br><br>Address & be<br>living in USA,<br>served between<br>2007-2008. | Logistic<br>regression | 14-25% showed<br>worse mental<br>health from T1 to<br>T2. Younger age<br>(SE = 0.95, p<0.01)<br>& recent medical<br>care (SE = 1.37,<br>p<0.01) associated<br>with increased<br>alcohol use. Lack<br>of deployment<br>training associated<br>with worse PTSD | Mental health<br>may decline<br>over time<br>among<br>veterans.<br>Identification<br>of indicators of<br>vulnerability to<br>subsequent<br>difficulties |

|                                      |   |      |                           |   |  |                          |                                  |   |   |
|--------------------------------------|---|------|---------------------------|---|--|--------------------------|----------------------------------|---|---|
|                                      |   |      |                           |   |  |                          |                                  | symptoms  |   |
| Pietrzak et al. (2011)<br><i>USA</i> | Examine combat experiences associated with PTSD & symptom clusters              | PTSD | Anonymous mail survey     | PCL-M, CES  | N= 285<br>Mean age= 34 (SD 0.6)<br>M= 88.8%<br><br>No PTSD, mean= 31.1 (SD 1.2)<br>27.1% return rate<br>Service between January 2003- March 2007 | All Connecticut veterans | Bivariate correlations           | Witnessing someone from ones unit/ ally being seriously wounded or killed (OR = 4.34, p<0.001) / exposure to 'friendly fire' (OR = 2.94, p< 0.05) & land mines associated combat-related PTSD | Risk of combat PTSD symptoms may be related to combat experiences           |
| Polusny et al. (2011)<br><i>USA</i>  | Identify pre trauma, trauma & post trauma risk factors for developing new-onset | PTSD | Prospective, longitudinal | Readiness & Resilience in National Guard Soldiers Study. Questionnaire design (pre) & | National Guard Troops<br><br>N= 522 (pre deployment) N= 424 (2-3 months post deployment)   |                          | Hierarchical logistic regression | 13.8 new-onset probable PTSD diagnoses post-deployment. Linked more stressors (OR = 2.20, p<0.001), not   | Combat exposure may be unavoidable, but other vulnerability factors predict |

|                           |   |      |                                    |   |   |  |  |   |  |
|---------------------------|---|------|------------------------------------|---|---|--|--|---|--|
|                           | PTSD  |      |                                    | mailed survey (post). PCL, PCL-C, PLC-M.  | M= 462 (88.5%), F= 60 (11.5%)<br><br>Between 18-29 years N= 313 (60%), 30+ years N= 209 (40%) |  |  | feeling prepared (OR = 0.58, p<0.01), combat exposure (OR = 2.19, p<0.001)/ aftermath (OR = 1.62, p<0.05)   | PTSD as well. Social support protective factor   |
| Elbogen et al. (2010) USA | Identify risk factors associated with post deployment anger and hostility | PTSD | Cohort study using MIRECC registry | Veteran volunteers following September 11 2001. Traumatic Life Events Questionnaire, Davidson Trauma Scale, Combat Exposure Scale, 90 hostility scale | N= 676, Median age= 36, 19.53% F  |  | Spearman Correlation, multiple logistic regression | Outcome measures of anger & hostility associated with PTSD hyperarousal symptoms (OR = 1.09, p<0.001). TBI (r = 0.11, p<0.1) & alcohol misuse (r = 0.15, p<0.001) related to outcomes | Risk factors of anger and hostility include previous conflicts, family violence, hx of abuse & combat exposure |

|                                    |   |                              |  |                                      |   |  |  |   |   |
|------------------------------------|---|------------------------------|--|--------------------------------------|---|--|--|---|---|
| Rona et al. (2009)<br><i>UK</i>    | Contribution of baseline symptoms, combat exposure & unit support in etiology of PTSD       | PTSD/ psychological distress | Prospective. Questionnaire at baseline & follow-up                       | Random selection. PCL, GHQ-12, SF-36 | N= 1828<br><br>Naval Services, Army & RAF |  | Multiple logistic regression   | Baseline psychological symptoms, combat exposure ( $X^2 = 58.43, p < 0.001$ ), unit support ( $X^2 = 8.40, ns$ ) associated with outcomes. Combat exposure effect size marked for PTSD (OR = 3.3, $p < 0.001$ ) | Combat exposure & group cohesion influence risk of mental health difficulties regardless of previous mental health status |
| Ursano et al. (2014)<br><i>USA</i> | Identify risk and resilience factors for suicidality and its psychopathological correlates. | Suicide                      | Comprises 6 main component studies: HADS, SHOS-A/B, NSS, AAS, PPDS, PPSS |                                      |   | Measures (self-report and administratively recorded) suicidal behaviours and psychopathological correlates | 13.9% currently active non-deployed regular Army soldiers considered suicide | Deployment, demoted within past 2 years, prior mental disorder. Of active non-deployed soldiers 13.9% considered suicide, 25.1% met DSM-IV criteria for   | Identification of risk factors of suicide and the importance of suicide prevention for the army                           |

|                             |   |                            |   |         |  |                           |  |  |   |
|-----------------------------|---|----------------------------|---|---------|--|---------------------------|--|--|---|
|                             |   |                            |   |         |  |                           | during lifetime                            | anxiety, mood, disruptive behaviour or substance disorder  |   |
| Lemaire & Graham (2010) USA | Investigate associations of known risk factors, effects of PTSD & depression on suicidal ideation | Suicide/ suicidal ideation | Cross-sectional retrospective review of routine psychological evaluations using semi-structured clinical interviews & records over a four-year period. From Houston VA Medical Centre TRP | DRRI    | N= 113, Mean age= 29.4 (SD 8.4) years, 84.1% M | Unclear screening methods | Kruskal-Wallis, ANOVA, logistic regression | Prior suicide attempts (OR = 4.71, p = 0.001), female gender (OR = 3.18, p = 0.002), existing diagnosis (co-morbid depressive disorders and PTSD- specifically avoidance symptoms), concerns relating to military role | Several risk factors for suicide identified. Focus on intervention to mitigate these and bolster protective factors |
| Browne et                   | Military  | Heavy                      | Cohort study,   | Devised | N= 662, 23% (N=                                | Inc- male, role           | Univariable                                | Lower rank, single,  | Deployment  |

|                         |   |          |                     |   |                                  |  |                                     |  |  |
|-------------------------|---|----------|---------------------|---|----------------------------------|--|-------------------------------------|--|--|
| al. (2008)<br><i>UK</i> | deployment factors that are associated with heavy drinking (WHO definition) | drinking | questionnaire-based | questionnaire booklet, GHQ-12, PCL-C, WHO AUDIT | 1047) between 30-34 years, 92% M | in Operation TELIC 1 (Jan-April 2003), heavy drinkers, deployed regular personnel with UK Armed Forces<br><br>Exc- women (small number of heavy drinkers) reserves (different health status) | & multivariable logistic regression | younger, naval service or army, no children, smoker, combat role, parent with drink or drug problem. Deployed with parent unit (OR = 1.28), medium (OR = 1.35) to high (OR = 1.35) comradeship, poor unit leadership (OR = 1.78), home problems (OR = 1.33) p<0.001 for all) | experience, problems at home and unit influence risk. More heavy drinking in this group compared with the general population |
|-------------------------|---|----------|---------------------|---|----------------------------------|--|-------------------------------------|--|--|

\* For brevity, where a range has been used for age this represents the largest group in the sample

**Abbreviations (as per AMA Manual of Style and author guidelines)**

AAS= All Army Study; AUDIT-C= Alcohol Use Disorders Identification Test; CES= Combat Exposure Scale; CHAMPS= Career History Archival Medical and Personnel System; DMSC= Defence Manpower Data Centre; DRRI= Deployment Risk and Resilience Inventory; GHQ-12= General Health Questionnaire; HADS= Historical Administrative Data Study; MH; Mental Health MIRECC= Mid-Atlantic Mental Illness Research, Education, and Clinical Centre; NGR= National Guard Reserves; NSS= New Soldier Study; OR= Odds Ratio; PCL= Posttraumatic Disorder Checklist; PCL-C= Civilian version; PCL-M= Military Version; PPDS= Pre-Post Deployment Study; PPSS= Pre-Post Separation Study; RR= Relative Risk, RINGS Cohort= Resilience in National Guard Soldiers; SF-36= Short Form (36) Health Survey; SHOS- A/B= Soldier Health Outcomes Studies A and B; SE= Standard Error, TBI= Traumatic Brain Injury; TRP= Trauma Recovery Programme; VA= Department of Veterans Affairs; WHO AUDIT= Alcohol Use Disorders Identification Test; WHO= World Health Organisation

## **1.6. Critical appraisal**

### ***Quality assessment of included studies***

To rate the methodological quality of studies meeting the inclusion criteria in relation to the systematic review question, a quality assessment checklist was developed (see *Appendix 2*). It was devised from principles outlined in the Scottish Intercollegiate Guidelines Network (SIGN) 50 Guideline Developer's Handbook and Critical Appraisal Checklists for cohort and case-control studies (SIGN, 2014), the Cochrane Review Handbook (Higgins and Green, 2013), and Centre for Reviews and Dissemination Guidance (CRD). In addition, quality assessment was based upon the primary research non-intervention studies (Kmet et al., 2004) and quality assessment criteria for reviewing non-intervention studies used by the Eppi-centre (Harden et al., 2001). Quality criteria underwent further refinement derived from the Critical Appraisal Skills Programme (CASP; 2014) CASP Cohort Study Checklist, and Tooth and colleagues (2005) 33 item checklist criteria for reporting on observational longitudinal research. Tooth and colleagues (2005) checklist suggested criteria related to recruitment, data collection, biases, data analysis, descriptive issues regarding study rationale and population, and generalisability. These additional tools were used to appraise included studies to gain information on this clinically relevant area so it was possible to differentiate between study results by reviewing each individual quality score. The checklist underwent three revisions before the final version was used to rate studies (see *Appendix 2* for final version).

### ***Inter-rater reliability***

As a degree of subjective analysis and therefore potential for bias in this process of quality assessment exists, SIGN (2014) recommend the quality assessment should also be undertaken by a second researcher in order to ensure consistency. In order to ascertain the reliability of the rating scale a random sample of five papers were coded by two separate investigators in addition to the main author. There was full agreement on 69.09% (38/55) of ratings, a difference of one point on 20% (11/55) of ratings and a difference of two points on 10.09% (6/55) of ratings. The number of agreements expected by chance was 31.54% (17.3/55). Where discrepancies

occurred discussions took place and ratings for the criteria were reviewed and amended where appropriate.

Cohen's Kappa was run to determine if there was agreement between the three raters' judgements on quality rating of the papers. There was moderate agreement between the three raters' judgements,  $K = 0.549$ ,  $SE = 0.091$ , 95% confidence interval (from 0.369 to 0.728) (calculated from <http://graphpad.com/quickcalcs/kappa1/>).

### ***Quality of included studies***

Methodological quality of included studies was rated on a three-point scale applied to 11 criteria (equally weighted, see *Table 2*). Each paper was allocated a quality rating: excellent (3 points, ++), very good (2 points, +), reasonable (1 point, -) and limited, not applicable or not reported (0 points, --). The maximum score obtainable was 36 (11 criteria multiplied by score of 3). An overall percentage was calculated by dividing the total score (11 criteria multiplied by the score (0, 1, 2 or 3) by total of 36 and then multiplying this by 100.

The quality ratings for the ten studies over the 11 quality criteria, including a total quality rating, are presented in *Table 2*. It is important to note that this is not an exact comparative measure, however, it does provide an indication of the methodological strengths and weaknesses of each study.

According to these criteria, Booth-Kewley and colleagues (2013), Polusney and colleagues (2011) and Schultz and colleagues (2014) conducted the methodologically strongest studies. The majority of studies were of average (or reasonable) quality, with one study by Pietrzak and colleagues (2011) having relatively limited methodological quality in relation to the review question.

**Table 2: Quality assessment for included studies**

| Study reference            | Quality assessment    |            |              |                  |                      |                    |             |           |           |                      |                     |                 |
|----------------------------|-----------------------|------------|--------------|------------------|----------------------|--------------------|-------------|-----------|-----------|----------------------|---------------------|-----------------|
|                            | Theoretical framework | Study aims | Study design | Selection method | Eligibility criteria | Outcome measure(s) | Sample size | Attrition | Follow-up | Statistical analysis | Data interpretation | Total score     |
| Booth-Kewley et al. (2013) | +                     | ++         | ++           | +                | ++                   | +                  | +           | +         | ++        | ++                   | ++                  | 28/36<br>77.78% |
| Browne et al. (2008)*      | +                     | +          | ++           | ++               | +                    | +                  | +           | +         | -         | ++                   | ++                  | 24/36<br>66.66% |
| Elbogen et al. (2010)      | +                     | +          | +            | ++               | +                    | ++                 | --          | --        | --        | ++                   | +                   | 19/36<br>52.77% |
| Lemaire & Graham (2010)    | ++                    | ++         | ++           | +                | -                    | +                  | --          | -         | --        | +                    | ++                  | 20/36<br>55.55% |
| Pietrzak et al. (2011)     | +                     | ++         | ++           | --               | +                    | ++                 | --          | --        | --        | -                    | ++                  | 17/36<br>47.22% |
| Polusney et al. (2011)     | ++                    | ++         | ++           | +                | +                    | ++                 | --          | ++        | ++        | ++                   | ++                  | 28/36<br>77.77% |
| Rona et al. (2009)         | +                     | ++         | ++           | +                | +                    | +                  | -           | +         | ++        | ++                   | ++                  | 26/36<br>72.22% |
| Schultz et al. (2014)*     | +                     | ++         | ++           | ++               | ++                   | ++                 | -           | ++        | +         | ++                   | ++                  | 29/36<br>80.5%  |

|                         |   |   |    |    |   |   |    |    |    |   |   |                 |
|-------------------------|---|---|----|----|---|---|----|----|----|---|---|-----------------|
| Seal et al.<br>(2009)   | - | - | ++ | ++ | + | + | ++ | -- | ++ | + | + | 22/36<br>61.11% |
| Ursano et al.<br>(2014) | - | + | ++ | +  | + | + | ++ | -  | -- | + | + | 20/36<br>55.55% |

**3 points (++):** Excellent

**All or considerable majority** of the criteria have been well covered. Limitations of the study are thought to be *very unlikely* to have affected the findings or conclusions.

**2 points (+):** Very good

**Considerable majority** of the criteria have been well covered or adequately addressed. Limitations of the study are thought to be *unlikely* to have affected the findings or conclusions.

**1 point (-):** Reasonable

**Majority** of the criteria have been well covered or adequately addressed. Limitations of the study may have modestly affected the findings or conclusions.

**0 points (--):** Limited

Many or most criteria were not well covered or adequately addressed. Limitations of the study are thought *likely or very likely* to have affected the findings or conclusions.

**0 points (--): Not Applicable (NA) Not Reported (NR)**

- For Browne et al. (2008) the sampling methods, participants, measures used and information regarding response rates and characteristics of non-responders were sourced from Hotopf et al. (2006)
- For Schultz et al. (2014) more detail regarding data collection procedures were obtained from Vogt et al. (2011) and Eisen et al. (2012)

## ***Data synthesis***

Heterogeneity in terms of interventions, measures and outcomes, and insufficient statistical information in some studies meant that a meta-analysis was not appropriate. Extracted data were synthesised using a narrative approach.

### **1.7. Comparison of quality of included studies**

#### ***Theory testing (theoretical background, study aims and data interpretation)***

All of the studies provided clear aims consistent with identifying risk factors for mental health problems among returning OEF and OIF veterans. Among studies, a range of terms were used to identify and categorise types of risk factors including emerging, new onset, worsening, pre-deployment, during, and post deployment risk factors. This was barring Seal and colleagues (2009) whose study was commissioned to identify prevalence and high-risk subgroups for mental disorders in order to develop targeted mental health services within the Department VA in the US. Although this study scored poorly on the basis that it did not provide an adequate literature review or clear aims, overall it was found to be methodologically strong. Browne and colleagues (2008) was the only study with emphasis on deployment factors associated with heavy drinking, scoring 'very good' in this quality criterion.

The majority of studies (8/10) gave some theoretical background and included a robust literature review linking their proposed research to an existing knowledge base. Two studies in particular (Lemaire and Graham, 2010; Polusney et al., 2011) were found to be very strong in this area. All of the studies provided sufficient original data to discuss results and conclusions substantiated by the data with the exception of Ursano and colleagues (2014), who synthesised findings from a number of component studies; therefore scoring poorly in relation to this quality criteria.

#### ***Outcome measures and follow-up***

Risk factors were identified in a number of different ways depending on the aims of the study. Approximately half of the studies had a relative strength in terms of the

choice and applicability of outcome measure used. Many of the studies (n = 3) used military medical records from the VA or pre-existing medical military datasets and self-report questionnaires (n = 8) at set time-points throughout the follow-up period (n = 5). A minority used both self-report methods alongside accessing military medical records (n = 2). Lemaire and Graham (2010) additionally administered semi-structured clinical interviews. Booth-Kewley and colleagues (2013) study used psychiatric diagnosis as the primary desired outcome over the course of the follow-up period.

Half of all studies circulated the Posttraumatic Stress Disorder Checklist (PCL, Weathers et al., 1993) in either the military (PCL-M) or civilian (PCL-C) form. The PCL is a self-report rating scale of the symptoms of PTSD in accordance with the DSM-IV and so is widely used in the area of veterans' research. The PCL has excellent test-retest reliability and internal consistency is high for items corresponding to the DSM-IV symptom clusters, as well as the full 17-item scale. The PCL also correlates highly with other measures of PTSD (Weathers et al., 1993).

Three studies used the Deployment Risk Resilience Inventory (DRRI; Vogt et al., 2013; Lemaire and Graham, 2010; Schultz et al., 2014). Pizetrak and colleagues (2011) was the only other study that used a specific military measure appropriate to their primary research question, namely the Combat Exposure Scale (CES), which assesses wartime stressors based on exposure to combat situations. The CES has been shown to have sound psychometric properties with Vietnam-era veterans (Keane et al., 1989).

Only four studies had a follow up period of one year; receiving 'excellent' ratings according to the quality criteria. Of these, two administered pre and post measures via postal surveys alone (Booth-Kewley et al., 2013; Rona et al., 2009). Five studies did not have a follow-up period, collecting measures at a single point in time. Browne and colleagues (2008) received a 'reasonable' score because although their study collected data at a single time point, it also synthesised these findings with previous findings from the same cohort from another study (Hotopf et al., 2006).

### ***Statistical analysis***

All of the reviewed studies reported descriptive statistics and used appropriate statistical analyses to identify risk factors among veterans. The majority (n = 7) also discussed demographic and clinical confounding factors, which could have an impact on risk and any adjustments made in statistical analysis. With the exception of Seal and colleagues (2009), all other studies used regression models in their analyses.

Ursano and colleagues (2014) reported findings from the multi-component studies independently, although their results are considered together in order to avoid overstating the findings. They did however receive a 'very good' rating as the paper discussed data adjustments and time-space clustering, and the impact of these on estimating statistical significance. They found that design effects (Kish, 1965) were quite low ( $D_{\text{eff}}$  1.0-1.9) meaning that the component studies' complex sample designs were nearly as efficient as simple random samples for estimating prevalence of Army Risk and Resilience in Service members measures (Kesler et al., 2013). These included self-report and administratively recorded measures of suicidal behaviours and their correlates across the six main component studies comprising their synthesis.

### ***Representativeness (selection method, eligibility criteria, sample size and attrition) and study design***

The included studies were investigated to ascertain whether the sample was representative of the OEF and OIF veteran population, meaning that findings could be generalised. The majority of studies used random or representative sampling. Two were based on reviewing medical records and therefore did not involve any direct contact with veterans. Pietrzak and colleagues (2011) selected their target sample of 1050 Connecticut veterans who served since 2003 alphabetically by surname from discharge papers. This was due to the vast number of eligible veterans. As the study by Ursano and colleagues (2014) comprised six main variable component studies, it was difficult to synthesise and, therefore, to draw any meaningful conclusions regarding representativeness.

There was considerable variability between veteran study populations. Barring three (Booth-Kewely et al., 2013; Polunsky et al., 2011; Rona et al., 2009), the remaining studies focussed on OEF and OIF veterans covering all aspects of the military. Therefore, they may be more representative of the general veteran population as they cover a greater range of potential military exposures consistent with the combat period. Two studies drew their sample from the Resilience in National Guard Soldiers (RINGS, Polunsky et al., 2011) cohort-study population.

Three of the studies focussed primarily on identifying risk factors for general mental health, whereas the remainder focussed on specific mental health diagnosis including PTSD, suicide and risk associated with increased suicidality, and military deployment factors associated with heavy drinking.

Nine papers demonstrated clear eligibility criteria, scoring strongly in this area, and included veterans who had active duty in previous deployments. A number of studies excluded reserves on the basis of their different health status. However, Lemarie and Graham (2010) provided no information on study eligibility.

Browne and colleagues (2008) excluded women on the grounds that they comprised a small number of heavy drinkers ( $n = 64$ ) and reserves because of their different prevalence of heavy drinking (18.5% versus 11.5% respectively,  $p < 0.001$ ). Due to the nature of the veteran population, often the number of female participants was limited in studies. However, in their study Schultz and colleagues (2014) oversampled women to comprise 50% of their population. There was also a huge variation across studies in terms of sample size. This ranged from 113 participants (Lemarie and Graham, 2010) to 289328 participants (Seal et al., 2009).

Schulz and Grimes (2002) suggest that loss to follow-up of less than 5% will, generally, not bias data, whereas loss of 20% or more can indicate that bias has been introduced. Two of the studies had attrition of at least 80%, three had rates of at least 60%, and two had rates of at least 40%. Therefore, half of the studies scored

poorly in this domain, as they did not address the issue adequately or at all in some cases. Therefore, the generalisability of the findings may have deteriorated as participants who stayed in the studies and completed follow-up may differ from those who did not, leading to biased results. Of these studies, none reported baseline characteristics of veterans lost to follow-up independently from those included in the analysis.

With the exception of one study (Elbogen et al., 2010), all of the other studies scored 'excellent' in respect to study design. Almost all of the studies (n = 8) used a retrospective longitudinal design to assess changes over a period of time in order to identify potential risk factors. Two studies used a cohort design; one used an observational approach, and one an anonymous mail survey.

#### ***Key findings in the context of methodological quality of studies***

Four of the studies focussed on general mental health. Of these, Schultz and colleagues (2014) found that a lack of deployment training was associated with more severe PTSD symptoms. Their study was one of the strongest methodologically as it used an observational design of a random sample of 512 returning veterans that were surveyed firstly between three and 12 months after returning, and then again six months later.

In Booth-Kewely and colleagues (2013) study, active duty, younger age (less than 25 years old), combat exposure and recent medical care were associated with increased risk of mental health problems. Satisfaction with leadership was found to reduce risk of receiving a mental health diagnosis (Booth-Kewley et al., 2013). This study was found to be methodologically strong as it was a longitudinal investigation of 1113 marines using demographic and psychosocial predictor variables in relation to subsequent psychiatric diagnosis. However, the predictor variables were based on self-report and used identifiable information, and it is likely that the study lacked power to detect small effect sizes.

Four studies focussed on PTSD specifically, including the other methodologically strongest study as well as the weakest study (Polusny et al., 2011; Elbogen et al., 2010, respectively). In terms of risk for developing combat-related PTSD, three studies found that combat exposure was associated with increased risk. Other factors included witnessing someone from ones unit or an ally being seriously wounded or killed, exposure or dealing with the aftermath of 'friendly fire' and land mines, more stressors or not feeling prepared for combat, and lack of unit support. Elbogen and colleagues (2010) found that the outcome measures of anger and hostility were associated with PTSD hyper-arousal symptoms. However, this study was subject to difficulties in inferring association between symptoms given the cross sectional nature of analysis. Further, Pietrzak and colleagues (2011) established that risk of combat PTSD symptoms may be related to combat experiences and although this may be unavoidable, Polusny and colleagues (2011) suggests that support is a protective factor.

Two studies (Lemaire and Graham, 2010; Ursano et al., 2014) focussed specifically on risk of suicidality and/ or suicidal ideation. Combat role, deployment and being demoted within two years all increased risk. Individual characteristics for this increased risk included prior suicide attempts, female gender and having an existing diagnosis; specifically of depressive disorders and PTSD (avoidance symptoms) relating to military role.

Browne and colleagues (2008) study was the only one to look at military deployment factors associated with heavy drinking. They identified a range of risk factors and found deployment experience, problems at home, and unit, all influence risk. They also found heavier drinking in this group compared with the general population.

Two of the studies found that women were at greater risk for mental health problems, including depression (Seal et al., 2009) whereas men were found to be at increased risk if they had drug use disorders. Lemaire and Graham (2010) found that female gender (15.9% of sample) was associated with increased suicidal ideation (OR = 4.71, 95% CI: 1.51 – 6.72,  $p = 0.002$ ). However, these findings must be interpreted with caution given the underrepresentation of women in the sample, while also being mindful of how included women may not be representative of the veteran population as a whole. In Seal and colleagues (2009) study, women comprised 12.6% of active duty and 10.9% national guard and reserve veterans, and in Lemaire and Graham's (2010) study 15.9% of veterans.

## **1.8. Discussion**

This systematic review aimed to establish more clearly the risks for mental health problems to increase understanding of factors that contribute to symptomology and functional impairment in the veteran population. In light of the recent importance placed on mental health services for returning veterans it was anticipated that identifying risk factors specific to this population would further enable support to be

tailored to meet veteran's specific needs. All of the studies reviewed identified risk factors, although due to their heterogeneous nature key findings varied considerably.

The main finding that was consistently reported among studies comprising the review was combat exposure and deployment experiences were associated with emergence of post-deployment mental health problems. This was especially so for PTSD although it is difficult to discern if diagnosis is increasing due to military involvement or its increasing international recognition (Jones et al., 2007). Existing evidence suggests that combat exposure is not the only determinant of PTSD or mental health problems among military personnel, and factors such as non-combat associated stressors, such as being away from home and environmental differences, whilst deployed may influence mental health outcomes (Booth-Kewley et al., 2010). There is clearly a huge diversity in what is considered to be noncombat experience, and this is likely to vary depending on type and length of deployment as well as pre-enlistment and post-deployment factors.

### ***Combat exposure***

There are a plethora of studies linking the effects of deployment on PTSD, although variability in rates have made interpretation and comparison between military forces challenging. This may be due in part to different military units having different combat experiences. For example, type of service has been shown to have a significant role in subsequent risk of developing mental health problems in veterans, possibly because of the type of combat exposure (Solomon et al., 1994).

OEF and OIF have seen military personnel being exposed to a range of combat events in the absence of obvious front lines. These include ambush, suicide attacks, and improvised explosive device (IED) exposure (Hoge et al., 2004). A great deal of research supports the notion that military personnel, particularly those in combat roles are exposed to traumatic events and that prolonged exposure to these may increase risk of mental health problems, including PTSD, in proportion to the level of reported combat (Fear et al., 2010). Direct combat exposure to traumatic events,

such as, being wounded, opening fire at the enemy and seeing/ or handling human remains is the most consistently associated factor with mental health problems and symptomatology. The current review would support the assertion that combat risks, such as exposure to fire, and witnessing injury or death were linked with an increase in the emergence of mental health problems, including PTSD and as such warrant further investigation.

### ***Non-combatant experiences***

These encompassed a variety of experiences that could be reliably categorised under the heading of unit risks, such as, cohesion and preparedness for service. Therefore, a range of vulnerability factors may predict PTSD other than unavoidable combat exposure, for example, more stressors and not feeling prepared for service (Polusny et al., 2011).

There is some evidence that leadership and unit cohesion may have an impact on mental health problems in military personnel and that positive attitudes and perceptions of support are associated with greater job satisfaction and increased morale as well as overall sense of wellbeing (Booth-Kewley et al., 2013). Conversely, Castro and McGurk (2007) found that deployed personnel who rated their leadership command unfavourably were also more likely to screen positively for mental health problems. Therefore, positive leadership experiences may mitigate some of the negative psychological ramifications of deployment.

Furthermore, reserves may be at greater risk compared with deployed veterans (Greenberg et al., 2012). Findings suggest that the elevated risk among reserves could be related to different perceptions of risk, lack of team cohesion and peer support with regular personnel, and difficulties adjusting to life post-deployment (Dandeker et al., 2010; Browne et al., 2007; Vogt et al., 2008). In a study conducted by Harvey and colleagues (2011), they found reserves deployed to OEF and/ or OIF that had mental health problems were more likely to have experienced difficulties with post-deployment social functioning.

### ***Pre-deployment and post-deployment factors***

There is some evidence that PTSD symptoms are independently related to combat stressors and deployment. However, appraisal of stressor severity may be confounded by pre-existing bias. Polusny and colleagues (2010) found other vulnerability factors to predict mental health problems include prior stressful life events. This appears contrary to previous findings (Seal et al., 2009).

As noted above, it is likely that deployment can increase risk of experiencing mental health problems, as evidenced by increases in diagnosis among VA veterans following return from OEF and/ or OIF (Seal et al., 2009). Experiencing a mental health problem is likely to have a significant impact on adjustment to civilian life across all areas. In support of this assumption, Erbes and colleagues (2011) noted that having a mental health diagnosis can impair occupational functioning; with those that have a diagnosis less likely to be employed. Other factors that may also influence risk of experiencing mental health problems include previous family violence and history of abuse (Elbogen et al., 2010).

Meanwhile, being female was also associated with increased risk of developing a mental health problem. For example, Rundell and colleagues (2006) found that women deployed to OEF and/ or OIF were more likely to leave service due to mental health problems, and were more vulnerable to experiencing depression, anxiety and PTSD (Kehle et al., 2011; Riddle et al., 2007) when compared with male colleagues. Although the reasons for increased susceptibility among women is largely unknown, several studies have indicated that combat exposure may have a more detrimental effect on mental health among women. Factors such as sexual harassment and assault, lack of social support and marginalisation may also contribute to gender differences (Street et al., 2009). Although it is proposed that women are more likely to exhibit help-seeking behaviours, men may exhibit a greater propensity to internalising symptoms (including anxiety and depression) in response to combat (Zinzow et al., 2008). Despite evidence suggesting female gender may be a risk factor in itself for mental health problems, women were hugely under-represented in studies.

The available evidence suggests social support may be a protective factor for developing mental health problems (Polusny et al., 2011). Group cohesion can also influence mental health outcomes regardless of mental health status (Rona et al., 2009) as well as overall deployment experience (Browne et al., 2008). There is clearly a need for screening and early intervention tailored to specific groups as well as ongoing assessment for post deployment veterans. This will give valuable insights into important indicators of vulnerability to subsequent difficulties (Schultz et al., 2014).

To date no constructs or theories have been put forward to account for the documented association between risk factors and mental health problems in veterans. Perhaps this is because of the range of experiences and backgrounds that veterans have experienced, and the array of presentations and symptoms that veterans may come with (Hoge et al, 2004). Moreover, this is a relatively newly emerging area as awareness of mental health and intervention options become more readily available and accessible to veterans (Iversen et al., 2005; Gould, 2007). None the less this is an area in need of theory development and testing to further understand the associations and ultimately advance treatment efforts for veterans. The diathesis-stress theory (Zubin and Spring, 1977) may go some way to account for the vulnerability of certain veterans in so much that a veteran may have a pre-disposition (biological or early life experiences) that interacts with stress or life events that may subsequently serve as a catalyst to the development of a mental health problem. Therefore, if the combination of vulnerability and stress exceed a threshold, mental health problems may ensue. Conversely, protective factors can counteract the effects of the stressor. This approach also indicates several areas in which families can play an important role in improving mental health outcomes by bolstering protective factors (Dandeker, 2003), which may be an important area for future research. The findings of this review do provide some preliminary evidence that early life experiences and gender may increase susceptibility to mental health problems in veterans. However, if veterans are exposed to specific deployment experiences and critical combat exposure incidents this may increase risk and

prosperity to mental health problems in the absence of social and practical/ familial support upon return to civilian life.

### ***Limitations of the studies***

The representativeness of the samples in this review was inconsistent. For example, study populations were drawn from a range of military roles and, as such, included veterans that may have been exposed to very different operational experiences (due to the nature of their service). This is likely to impact on the generalisability of findings. Some studies also included reserves and deployed service personnel (Seal et al., 2009; Pietrzak et al., 2011). Although this has been addressed in the analysis, including reserves may have increased the likelihood of establishing risk factors given the evidence suggesting greater vulnerability to mental health problems among reserves (Hotopf et al., 2006). However, given the existing literature base it was impossible to differentiate the range of roles included within studies.

There was great variety in the measures and methods of data collection employed in the studies. The majority used reliable and valid measures specific to military populations, such as the PCL-M and DRRI, although for those who did not, this may have biased findings by identifying risk factors not accurately reflecting the experiences of the veteran population.

### ***Limitations of the review***

The main limitation of the review was the disparity between studies in relation to study sample, study design, and study outcome measures. This made comparison across studies extremely complex. Due to the heterogeneity of the studies comprising this review it was difficult to identify specific indices of increased risk among veterans in general and so synthesising and interpreting findings was difficult. In order to more effectively answer the review question, more longitudinal studies of veteran's mental health are needed in order to more clearly ascertain potential causal relationships. The majority of the included studies were cross-sectional examining deployment-related factors on post-deployment mental health outcomes. Here, there is a risk of introducing bias, as those with mental health problems may

perceive past events differently from those without symptomology. Some studies had the benefit of incorporating administrative and survey data to mitigate bias. However, longitudinal studies go further to help avoid biases.

Furthermore, publication bias may have been introduced, as this review excluded non-English language papers. An additional weakness of the current review was that there may be unpublished data that may have been relevant but not included, thereby further exasperating publication bias. This is of particular concern in a systematic review of observational studies as there is a greater threat of publication bias than with randomized controlled trials (Easterbrook et al., 1991). There may also be a potential of bias in the subjective recall of self-report questionnaires, therefore, it is imperative to consider the heterogeneity of study designs in relation to the results.

### ***Study implications and future research***

The results of this systematic review provide some strong evidence for potential risk factors in the subsequent development of mental health problems post deployment. The most common ones across studies were ~~deployment and~~ combat exposure/experiences, co-morbid mental health problem or alcohol misuse, lower rank, younger age, being single, decreased social support and female gender. Providing screening, followed by early intervention (tailored to specific subgroups known to be at increased risk) could potentially improve mental health outcomes among veterans and reduce demands on an already stretched mental health service.

In the US, OEF and/ or OIF veterans are currently eligible for two years of free military service-related health care from the Department of VA. Specific veteran services that have links to primary care settings would be central to early intervention as many initial mental health concerns are currently raised in non-mental health settings (Seal et al., 2007). At present, psychological debriefing represents the most common form of early intervention, although the evidence base as to its usefulness is sparse. An initial period of psychological 'first aid' may be a more appropriate intervention (Litz et al., 2002), as it can be administered prior to

discharge and may encourage subsequent help seeking, whilst also challenging stigma associated with accessing mental health services. This, in turn, might enable veterans to access an appropriate therapeutic modality. For example, early outreach focussing on community support post deployment may help to mitigate psychosocial difficulties and facilitate adjustment to civilian life, which has yet to be implemented (Pietrzak et al., 2010).

Involving family or the wider community in psychoeducation has also been found to decrease risk of developing mental health problems, through increasing awareness and understanding of mental health issues and how to promote recovery (SAMHSA, 2003). Pre-discharge programs emphasising practical and psychological preparedness and encouraging help seeking may also be helpful to reduce risk (Kapur et al., 2009).

Generic psychological support services for veterans have begun to be provided by statutory and non-statutory organisations. However, in a systematic review and meta-analysis of psychosocial interventions for veterans, Kitchiner et al. (2012) found 29 only randomised controlled trials, 28 of which were from the US and one from Australia. Of the 29 studies, only 12 had sufficient data available with which to judge the impact of service provision. In the UK, the limited service models that exist have not been systematically examined in the same way. In light of the increased awareness of indicators of vulnerability, this may be an important area of research in order that interventions could be meaningfully targeted to specific populations more effectively.

## **1.9. Conclusions**

The review was undertaken with the recognition that veterans' are likely to be at risk of mental health problems as a consequence of their military involvement, poor engagement with mainstream services, and due to a lack of dedicated service provision to meet the need of this unique population. The current review provides strong evidence that there are a number of specific risk factors that may increase

susceptibility to mental health problems post deployment. The majority of studies found some association between post deployment mental health problems, including PTSD, suicidality, and alcohol misuse and risk. Risk factors could broadly be categorised into unit cohesion, individual aspects, combat exposure and home circumstances prior to deployment. All of the studies to some degree were able to support this association. It is argued that interventions are needed in order to mitigate the risk factors and bolster protective factors.

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## Appendix 2: Criteria and scoring method for rating quality of reviewed studies

| Quality criteria                | Criteria definition  | Scoring   |   |  |  |
|---------------------------------|--|---|---|--|--|
|                                 |  | 3 points (++): Excellent  | 2 points (+): Very good   | 1 point (-): Reasonable  | 0 points (--): Limited   |
| <b>1) Theoretical framework</b> | The study was based upon a theoretical framework   | The study provides an explicit account of the theoretical framework and/ or includes a robust literature review which links the research to an existing body of knowledge | The study was based upon a theoretical framework and included an adequate literature review       | The literature review was inadequate and the study failed to make links between existing body of knowledge and research undertaken | Inadequate literature review, no discussion of how relates to current study    |
| <b>2) Study aims</b>            | Clear study aims outlined and discussed during interpretation in relation to data analysis | The study provides clear aims relating to identification of risk factors to mental health problems in veterans  | The study provides clear aims relating to identification of a variety of risk factors in veterans | The study provides limited justification of study aim in relation to research being undertaken                                     | Study aims highlighted but not discussed in relation to results or conclusions |
| <b>3) Study design</b>          | Type of study design rigorous to achieve study aims and adequately assess risk factors     | Prospective cohort, controlled longitudinal observation, case-control   | Observation without control   | Individual case studies, small N designs, reviews  | Poorly designed multiple subject design  |
| <b>4) Selection method</b>      | Sampling strategy clear  | Clear rationale,  | Sampling strategy and   | Lack of clarity in   | No information regarding   |

|                                |   |  |   |   |  |
|--------------------------------|---|--|---|---|--|
|                                | and justified   | justification and description of the circumstances under which the sample was recruited into the study. Random or representative sampling                            | recruitment adequately defined. Random or representative sampling   | describing how the sample were targeted and recruited into the study. Non-random or non-representative sampling | sample selection method  |
| <b>5) Eligibility criteria</b> | Study provides clear details of the sample used and are sufficiently alike in terms of drawing conclusions  | Inclusion/ exclusion criteria for veterans included in the study clearly defined and limitations identified to enable contextualisation of results                   | Inclusion/ exclusion criteria for veterans defined to enable replication  | Inclusion/ exclusion criteria for veterans poorly defined   | No information regarding inclusion/ exclusion criteria                                   |
| <b>6) Outcome measure(s)</b>   | Primary outcome measure(s) (including health outcome assessment/ diagnostic interview) evidenced to be valid and reliable, and measured in a standard | Standardised outcome measure(s) used with well-reported psychometric properties for population. Enables comparison from baseline to follow-up. Criteria followed and | Standardised outcome measure(s) used with well-reported psychometric properties, but not validated for population. Enables comparison from baseline to follow-up. | Diagnostic interview alone used or via self-report. Outcome measure(s) for one time point                       | No diagnostic interview or via self-report alone. Non-standardised outcome measures used |

|                                 |  |   |  |  |   |
|---------------------------------|--|---|--|--|---|
|                                 | way against set criteria   | adhered to for diagnostic interview   | Criteria followed for diagnostic interview using adapted format                              |  |   |
| <b>7) Sample size *</b>         | Sample size sufficient to enable analysis relating to longitudinal/ prospective follow-up                  | >15000  | 15000-5000   | 5000-1000  | <1000 or sample size too small for longitudinal analysis                  |
| <b>8) Attrition</b>             | Levels of attrition acceptable and clearly stated in study   | Attrition rates reported at each follow-up stage, sample numbers included in analyses clearly identified. Response rate at follow-up at least 80% | Attrition rates reported at follow-up. Response rate at follow-up at least 60%               | Attrition rates not reported in enough detail to ascertain sample size at follow-up. Response rate at follow-up at least 40% | Attrition was not addressed, response rate not reported                   |
| <b>9) Follow-up period</b>      | Baseline assessment enables comparison. Follow-up evaluation is appropriate to determine long-term outcome | Follow-up at one year or more   | Follow-up at six months or less  | Follow-up at three to six months   | No follow-up  |
| <b>10) Statistical analysis</b> | Analysis is appropriate to the design and outcome measure(s)   | A clear and detailed description of methodology, including overall research   | Adequate and suitable methods used to collect and analyse longitudinal/ prospective data. No | Inadequate methods used to collect and analyse longitudinal data, lacking detail to replicate. Poor                          | Methods not appropriate to study design making it impossible to replicate |

|                                |   |   |  |  |   |
|--------------------------------|---|---|--|--|---|
|                                |   | framework, and use of data collection and data analysis methods that are valid and reliable for longitudinal/ prospective data. Appropriate statistical method to deal with outliers and missing data to reduce bias  | statistical method to deal with outliers and missing data but outliers discussed and less 20% excluded from analysis | method used to deal with outliers and missing data, i.e. outliers included not considered and baseline scores carried forward to follow-up |   |
| <b>11) Data interpretation</b> | Sufficient original data to discuss results and conclusions substantiated by the data | Sufficient data to see results are grounded in the data. Data is linked to conclusions with alternative causal relationships considered. Interpretation and judgement about the validity and generalisability of findings discussed, i.e. explanation regarding number of | Data reporting is adequate in enabling the reader to see results and conclusions are grounded in the data presented  | Data reporting is inadequate in enabling the reader to see that results and conclusions are grounded in the data                           | Results and conclusions are not grounded in the data provided |

|  |  |                     |  |  |  |
|--|--|---------------------|--|--|--|
|  |  | predictor variables |  |  |  |
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\* Adapted from Buckman et al. (2010)

**A cross-sectional study investigating the impact of disease activity and  
disease related cognitions on adjustment in Inflammatory Bowel  
Disease**



**THE UNIVERSITY  
of EDINBURGH**

**Submitted:** May 2017

**Journal Format:** Inflammatory Bowel Diseases

The journal's author guidelines for structure, style and referencing have been followed and can be found in *Appendix 1*. Adaptations have been made for coursework submission guidelines

Submitted in part fulfilment of the degree of doctorate in Clinical Psychology at the  
University of Edinburgh

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**Declaration of Interest:** None

**Word Count:** Abstract: 270 words; Main Report: 7473 words

## **Abstract**

**Background** Adjustment to a diagnosis of Inflammatory Bowel Disease (IBD) can present significant challenges which may affect several patient-reported outcomes. The present study had two main aims; (1) To investigate the relationship between disease activity and illness related cognitions on Quality of Life (QoL) and, (2) To assess the degree to which psychological illness related cognitions will mediate the effect of disease activity on Quality of Life (QoL). A further subsidiary analysis was carried out to explore the extent to which disease and psychological variables might predict psychosocial adjustment outcomes.

**Methods** A cross-sectional design was used. Three hundred and thirty-eight participants were recruited through an IBD charity; with each participant responding to online self-report questionnaires. Measures targeted disease activity, several psychological factors (e.g. stigma) and different psychosocial adjustment outcomes.

**Results** Except for stigma, most psychological variables were significantly associated with all outcomes including QoL. Mediation analysis found support for significant indirect effects on the relationship between disease activity and QoL through Gastrointestinal (GI) anxiety, perceived disability and illness representations. The exploratory subsidiary analysis found the outcomes of stress, depression, anxiety, QoL, mastery, activity engagement (progression and obstruction) were found to be consistently predicted by perceived disability, illness representations, pain catastrophising and GI anxiety.

**Conclusions** The overall findings from this study suggest a range of adjustment indicators that have a significant role in patients with IBD and may be an important risk factor for poorer QoL and psychological functioning. The current study has provided insight into psychosocial functioning and adjustment indicators from a multi-faceted perspective, which will facilitate advancement of managing IBD from a biopsychosocial framework with a view to enable more effective disease management.

**Keywords**

Inflammatory bowel disease; psychosocial factors, adjustment; psychological functioning, quality of life

## **1.2. Introduction**

Inflammatory Bowel Disease (IBD) encompasses a variety of autoimmune diseases with the most common types being Crohn's Disease (CD) and Ulcerative Colitis (UC) (Taft et al., 2009). According to the British Society of Gastroenterology (2009), one in every 250 people are affected by IBD, with an estimated cost to the NHS of £720 million per annum. Diagnosis usually occurs between the ages of 10 and 40 years, with men and women equally affected (Taft et al., 2009). These conditions are chronic and unpredictable with alternating periods of active illness and remission (Larsson et al., 2008). Currently there is no cure; perhaps due to the aetiology of IBD being largely unknown (Larsson et al., 2008). The devastating impact IBD can have upon sufferer's lives, however, is well documented; with significant burden from symptoms and treatment demands throughout the life span frequently impacting negatively upon wellbeing and functioning in multiple domains (Taft et al., 2009).

The two main forms of IBD, namely CD and UC have a very similar symptom profile and it is often difficult to discern and diagnose which form a patient is suffering from (Liz et al., 2008). Some people with IBD, particularly those with CD may experience additional complications such as strictures and fistula although broadly speaking symptoms are shared, characterised by an abnormal response of the immune system on the digestive system (Searle and Bennett, 2001). For these reasons the literature and research evidence to date has tended to consider IBD as a chronic illness characterised by periods of remission and disease exacerbation. Research has shown that disease related cognitions and disease activity can potentially impact on the physiologic functioning of the gastrointestinal tract and decrease resilience to inflammation resulting in poorer psychological and psychosocial outcomes (Kiebles et al., 2010).

In an attempt to modify disease impact, patients with IBD require a strong set of self-management skills if they are to adhere to prescribed treatment protocols that often recommend significant changes to lifestyle (such as smoking cessation, diet control and stress management; D'Inca et al., 2007). IBD treatment emphasises

managing the inflammatory response during active episodes and maintaining wellbeing during periods of remission. Within this context, maintenance of a healthy lifestyle is encouraged, usually in combination with a strict medication regime (Kane et al., 2003). Indeed, adherence to medication is a major factor in determining outcomes and risk of relapse (Tae et al., 2016). The most common risk factors for non-adherence are younger age, busy work life, forgetting to take medication, and recency of diagnosis (D’Inca et al., 2007; Tae et al., 2016). In addition, patient self-efficacy potentially influences adherence; as perceived ability to carry out those behaviours that are required to be followed in order to control disease symptoms is likely to profoundly affect the degree to which an individual will engage in management behaviours and persist with treatment (Keefar et al., 2011).

### **Adjustment to IBD diagnosis**

At the point of receiving an IBD diagnosis, the individual’s psychological response typically activates both an emotional and behavioural reaction; with feelings of distress and grief, and seeking of social support commonplace (Kiebles et al., 2010). It is generally accepted that there is an initial transition period, during which a process of psychological adjustment to diagnosis takes place (Kiebles et al., 2010). Healthy psychological adjustment is reflected in successful adaptation to disease specific demands (such as coping with unpredictability) and demonstrating durability when it comes to maintaining psychological well-being, functional status and Quality of Life (QoL) both through and beyond the initial transition period (Kiebles et al., 2010).

Importantly, Kiebles and colleagues (2010) found that psychological adjustment may contribute to a variety of patient-reported outcomes in IBD, including disease acceptance, coping, activity engagement and perceived stress. In addition to this, the authors also found that age of disease onset, disease severity, health beliefs, behavioural responses and disease impact all, potentially, influence psychological adjustment. Due to the relapsing-remitting nature of IBD, the degree to which each

of the aforementioned factors becomes relevant, in terms of their influence on coping, is likely to fluctuate, with vulnerability to experiencing feelings of helplessness continuing to loom over IBD patients (Leslie et al., 2009).

There is a growing body of evidence suggesting that a number of psychological variables, that are potentially modifiable, help explain individual differences in adjustment to IBD (Kiebles et al., 2010). For instance, Jordan and colleagues (2016) identified a range of psychological correlates of adjustment in IBD. Broadly divided into four constructs, (1) personality traits (for example, neuroticism), (2) high perceived stress, (3) emotion regulation (for example, alexithymia) and (4) cognitions (for example, IBD illness perceptions relating to disease impact). Maladaptive characteristics or responding in the above ways were related to poorer adjustment outcomes including in QoL, psychological wellbeing and functional status (for example, activity participation). These authors also found that dysfunctional emotion focussed coping strategies (for example, attempting to minimise, reduce or prevent emotional responses), were associated with worse adjustment in IBD. In-keeping with the above findings, perceived stress has consistently been shown to influence adjustment outcomes (Tabibian et al., 2015) to the same degree as disease factors, for example, severity (Zhao et al., 2013).

Adjustment to IBD requires a unique set of adaptive skills to effectively adjust to the fluctuating nature of disease course and so can be viewed as a dynamic process. There are a number of key models in the literature focussing on adaptation to chronic disease. Hambrug and Adams (1976) suggest a number of tasks required in order to successfully adapt to living with serious illness, including; regulating distress, maintaining personal worth, restoring relations with significant others, pursuing recovery of bodily functions and increasing the likelihood of personally and socially acceptable situation once physical recovery is attained. In addition, Taylor's (1983) cognitive adaptation theory suggests establishing a sense of meaning as a fundamental adaptive task. Specific to physical characteristics of illness, Moos and Schaefer (1984) place emphasis on pain and symptom management, navigating the health care system and developing meaningful relationships with healthcare

professionals as important in adjustment. More recently, Spelten and colleagues (2002) conceptualise adaptation in terms of psychosocial functioning; specifically participating in paid employment, being involved in meaningful activities and mobility. Cella (2001) further highlights the importance of QoL as an indicator of successful adaptation. To date, little evidence exists in support of stage theories of adjustment to disease (Wortman and Silver, 2001) rather emphasis is on the multidimensional nature of adaption to disease specific demands.

Bearing the above in mind, it would seem fair to consider adjustment to IBD as a process that involves a complex and dynamic interplay amongst a diverse range of disease related and disease independent variables, such as intrapersonal factors. Taking account of this, IBD interventions should not only be aimed at modifying the disease itself but, as Jordan and colleagues (2016) point out, interventions should also focus upon improving coping, reducing perceived stress and management of IBD associated cognitions (for example, illness perceptions) with the ultimate aim of improving psychological adjustment and individual outcomes.

### **The impact of IBD on psychosocial functioning**

IBD can have a profound impact on an individual's psychosocial functioning across a range of contexts, including in employment, their social life, engagement in leisure activities and overall QoL (Kemp, Griffiths and Lovell, 2012). In a study by Adler and colleagues (2008) IBD diagnosis was found to be intrusive and disruptive of education and socialisation activities among college students. Significantly, research suggests that the negative impact experienced across domains may be more common in people with IBD when compared to both the general population and those affected by other chronic/ life-long conditions (such as arthritis and multiple sclerosis) (Graff et al, 2009).

Moreover, IBD has been found to be associated with an increased incidence of mental health problems compared to the general population and this, in turn, may be a predictor of lower HRQoL (Health Related Quality of Life; Iglesias-Rey et al.,

2016). Lower QoL as a result of the disease burden of IBD is correlated with less interpersonal support (Jones et al., 2006) and more passive coping styles (Larsson et al., 2008). Moreover, maladaptive emotional focussed coping strategies and negative illness perceptions have also been associated with reduced QoL in IBD, as well as increased psychological distress (Faust et al., 2012; Knowles et al., 2013). By contrast, better social and emotional functioning has been found to be linked with greater acceptance of symptoms and regular engagement with valued activities (Kiebles et al., 2010). In support of the powerful role of acceptance, McCracken and Eccleston (2003) found that greater symptom acceptance was significantly associated with reduced depressive and anxiety symptoms, and better QoL. These authors subsequently concluded that greater acceptance of pain (specifically) predicted more positive adjustment in IBD.

### **Psychological outcomes associated with IBD**

A biopsychosocial perspective of illness can provide a useful framework for understanding clinical outcomes and psychosocial consequences in IBD (Drossman, 1998; Maddux et al., 2013) and for advancement of management approaches in IBD (Mikocka-Walus et al., 2014). This is particularly true given that patients' psychological attributions regarding disease control can directly impact upon outcomes (Meyers and Janowitz, 1984) and findings reporting how emotion focussed coping strategies can result in poorer psychological functioning in IBD (McCombie et al., 2013). In keeping with such observations, both Leslie and colleagues (2009) and Gibson and colleagues (2007) found that those with IBD, particularly when in an active phase of disease, had poorer psychological function (including lower sense of mastery and higher levels of distress) when compared to those without IBD or another chronic illness. Porcelli and colleagues (1994) found patients experiencing current active disease reported higher levels of anxiety and depression compared to those in an inactive phase. They suggest current active disease status may be associated with poorer QoL and treatment response. However, this study did not allow the observation of possible impact changes in disease activity and psychological factors over time.

Furthermore, Bitton and colleagues (2008) found IBD patients were more likely to adopt unhelpful strategies to cope with stress, such as engaging in social diversion and distraction; with Mussell and colleagues (2004) highlighting how such tactics might contribute to higher levels of distress, more negative health and poorer post-operative outcomes.

### **1.3 Current study**

The aim of the current research is to extend current key models of adaptation to chronic disease, specifically in IBD, through looking at the mediating role of psychological illness related cognitions on psychosocial adaptation to disease specific demands. Current models purport the necessity of adaptive skills in order to adjust to the fluctuating disease course but the mediating role of illness related cognitions has yet to be investigated. It is hypothesised that; (1) More active disease and higher illness related cognitions will be associated with poorer QoL, and (2) Psychological illness related cognitions will mediate the effect of disease activity on QoL. This area warrants further investigation as previous research has suggested that increased disease activity is associated with poorer self-report outcomes of QoL in those with IBD specifically (Canavan et al., 2005; Sainsbury and Heatley, 2005) although the mechanisms underlying this have not been investigated to date. Therefore, Bearing the above in mind, exploration of the potential mediating role of psychological factors (in particular) may provide valuable insight into patient self-report outcomes in disease course. In this study, illness related cognitions as potential mediators were assessed using measures of perceived disability and stigma, illness representations, pain catastrophising and GI anxiety.

### **1.4 Subsidiary exploratory analysis**

In a study conducted by Kiebles and colleagues (2010), specific measures of adjustment (including perceived disability, emotional distress, emotional functioning and HRQoL) were identified. Kiebles and colleagues (2010) suggest individuals with

IBD who do not develop disease-specific adaptive strategies may be more likely to experience disruption to their life and, in turn, QoL may suffer. A number of proxy markers associated with psychological distress in IBD were identified including pain, greater perceived stress, engaging in fewer activities and more frequent utilisation of healthcare. However, Kiebles and colleagues (2010) study was limited by a convenience sample of only 38 individuals actively involved in a tertiary care clinic, whom had a longstanding diagnosis of IBD.

The subsidiary analysis was conducted in order to explore several psychological variables that might help us to better understand adjustment in IBD. This exploratory research will build on the existing work and address the shortcomings of the study conducted by Kiebles and colleagues (2010) and further investigate the impact of disease activity and several psychological factors (perceived disability and stigma, illness representations, pain catastrophising and GI anxiety), on several psychosocial adjustments outcomes in IBD (QoL, mastery, psychological functioning, treatment adherence and activity engagement). The subsidiary analysis aims to explore the extent to which disease and psychological variables might predict psychosocial adjustment outcomes.

## **1.5. Materials and methods**

### ***Study design***

An exploratory cross-sectional ~~correlational~~ mediation design was used. Participants were recruited through the IBD charity 'Crohn's and Colitis UK'. This was done by advertising on their website and using their research social media pages (and through their respective regional groups). The research was also advertised on other social media forums used by those with an IBD diagnosis including 'IBD Sucks' and 'Crohn's Zone'. A Web-based questionnaire was designed using the secure third-party survey provider 'Bristol Online Survey' and was embedded in a custom HTML website introducing the study to participants. <sup>1</sup>

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<sup>1</sup> Internet use among those with IBD has found to be high (81%) and individuals with IBD are likely to use the internet to find out information about their diagnosis (Cima et al., 2007). Given the high-traffic nature of the forums and the fact that

### ***Power analysis***

A medium effect size was expected based on guidance by Fritz and MacKinnon (2007) for detecting mediation effects. On this basis, a total sample size of 90 is required to achieve a power of 0.8 for mediation analysis. The effect size was estimated by looking at previous similar cross-sectional research such as that by Kiebles and colleagues (2010) and Lix and colleagues (2008). Using the bias-corrected bootstrapping technique employed in this study selected to detect mediation effects, an estimated sample of at least 71 participants is required according to the Fritz and MacKinnon (2007) guidance.

### ***Participants***

Data was obtained from a convenience sample of participants with self-reported diagnosis of IBD. Participants were invited to respond to a self-report questionnaire online between July 2016 and November 2016. All participants consented using an online consent procedure and completed the questionnaire using the same procedure via the 'Bristol Online Survey' portal.

### ***Inclusion criteria***

- Age 16 years of age or above;
- Participants should self-report that they have received a diagnosis of either CD or UC by a medical practitioner;
- Participant needs to be able to give informed consent and agree to participate in the research;
- An individual who is able to complete the self-report questionnaires.

### ***Exclusion criteria***

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'Crohn's and Colitis UK' itself has over 105,000 Facebook likes, was anticipated there would not be any difficulty in recruiting the required number of participants based on the number and geographical expanse of websites that will have links to the research. Moreover, it is estimated IBD affects one in every 250 in the UK, with around 120,000 people with UC and 90,000 with CD. Approximately one in 10,000 people receive a new diagnosis every year, and it usually begins in younger people aged 10-40 years (Centre for Disease Control and Prevention, 2009). For these reasons, it was estimated the desired number of people will access the research questionnaire, especially as newly diagnosed individuals are likely to be researching their diagnosis and potentially looking for support organisations in their area.

- An individual who is unwilling or deemed unable to provide informed consent to participate;
- An individual who has a comorbidity (self-reported) of Dyspepsia, IBS or a similar related condition.

### ***Procedure***

All measures were selected to assess (i) different aspects of the IBD profile, (ii) adjustment, (iii) psychological factors and (iv) QoL. Several socio-demographic (age, gender, race, marital status, educational attainment) and clinical (diagnosis, length of time since diagnosis, remission status, medication regimen) variables were also collected. IBD diagnosis was confirmed through a series of self-report clinical screening questions. Verification of disease status was achieved through requesting information about current medications. Participants were allowed to complete the questionnaire in an unlimited number of sittings and were informed it could take between 30 and 40 minutes to complete. Questionnaire responses were anonymously submitted to a secure server.

### ***Materials***

The self-report questionnaires included measures of:

#### **Psychological predictors**

##### **1) Catastrophising:** *Pain Catastrophising Scale* (PCS; Sullivan et al., 1995)

The PCS is a 13-item instrument asking respondents to reflect on past painful situations, and indicate the degree to which thoughts or feelings are experienced during pain on a four-item likert scale ranging from 0 (not at all) to 4 (all the time). This scale has been used in studies of IBD and has been found to be reliable (Cronbach's alpha was 0.87) and valid in clinical and non-clinical samples (Kuo et al., 2015).

##### **2) Disease activity:** *Harvey Bradshaw Index* (HBI; self report version; Harvey and Bradshaw, 1980)

The HBI is a five-item measure to assess disease activity, general wellbeing, abdominal pain and mass in the last day consistent with clinical measures. It also asks about complications arising from IBD. It was initially designed as a simpler version of the Crohn's Disease Activity Index (CDAI; Best et al., 1976) for research purposes and has been found equally as effective in assessing disease activity (Cronbach's alpha was 0.72).

**3) GI anxiety: *Visceral Sensitivity Index (VSI)*** (Labus et al., 2004)

The Visceral Sensitivity Index is a 15-item instrument designed to measure gastrointestinal symptom-specific anxiety on a six-item likert scale ranging from 1 (strongly agree) to 6 (strongly disagree). Respondents are asked the extent to which statements describing responses to symptoms or discomfort relate to them. It has been found to be a reliable (Cronbach's alpha was 0.93) and valid measure in IBS, an analogous condition, and so was selected for the purpose of this study.

**4) Illness representations: *Brief Illness Perception Questionnaire (Brief IPQ)*** (Broadbent et al., 2005)

The Brief IPQ is a 9-item questionnaire that measures cognitive and emotional representations of illness on a 10-item likert scale ranging from 0 (least) to 10 (most). A higher score represents a more threatening view of illness. It has been found to have good concurrent validity with the IPQ-Revised, which has good psychometric properties in the IBD population (Cronbach's alpha was 0.85) Kiebles et al., 2011). Although the brief version has not been validated for use with IBD patients, it was selected for use as a rapid assessment tool in larger-scale studies.

**5) Perceived disability: *Perceived Disability Scale (PDS)*** (Beckman et al., 2008)

The PDS is a 10-item questionnaire that assesses perceived limitations and disability associated with tasks of daily living. Patients report their current level of disability on a ten-item likert scale ranging from 0 (no disability) to 10 (total disability). Scores range from 0-100, with higher scores indicating greater perceived disability. It has been found to have good psychometric properties for use with individuals with IBD ((Cronbach's alpha was 0.92; Kiebles et al., 2011).

**6) Perceived Stigma:** *Perceived Stigma Scale in IBS* (PSS-IBS; Jones et al., 2009)

This is a twenty-item measure that assesses a range of areas of perceived stigmatisation in respect to a variety of social domains, on a five-item likert scale ranging from 0 (never) to 4 (always). Patients are asked to rate how often they have had a range of IBD experiences in relation to others they know and care providers. It has been found to be a reliable and valid measure of perceived stigma in IBD (Cronbach's alpha was <0.89; Taft et al., 2009).

**Psychosocial adjustment outcomes**

**1) Activities engagement:** *Valuing Questionnaire* (VQ; Smout et al, 2014)

The VQ is a 10-item measure assessing nine value domains on a six-item likert scale ranging from 0 (not at all true) to 6 (completely true). It has been found to have good reliability (Cronbach's alpha was 0.93) and validity in non-clinical samples although as yet has not been used with IBD patient research.

**2) Mastery:** *Perceived Health Competence Scale* (PHCS; Smith et al., 1995)

The PHCS is an eight-item domain-specific measure of the degree to which an individual feels capable of effectively managing health outcomes. Patients report the extent to which they agree or disagree with eight statements on a five-point likert scale. There is evidence for the reliability (Cronbach's alpha ranged from 0.82 – 0.90 across Smith and colleagues (1995) five samples) and validity of the PHCS in clinical and non-clinical samples. The PHCS has been used in studies with IBD patients looking at coping strategies in adjustment to IBD (Gandhi et al., 2014).

**3) Psychological functioning:** *Depression Anxiety and Stress Scales* (DASS 21; Henry and Crawford, 2005)

The DASS 21 is a 21-item questionnaire designed to measure the three related negative emotional states of depression, anxiety and tension/ stress on a four-item likert scale ranging from 0 (never) to 3 (almost always). It was not designed as a diagnostic tool. It has been found to be as reliable (Cronbach's alpha was 0.93 for

total scale) and valid as the original 42-item scale in non-clinical samples, and can usually be completed in less than three minutes (Henry and Crawford, 2005).

**4) Quality of Life:** UK Inflammatory Bowel Disease *Questionnaire* (IBDQ; Cheung et al., 2000)

The IBDQ is a 32-item measure that assesses health-related QoL specifically in IBD patients. Patients are asked to respond to questions indicating the extent to which they experience a particular bowel problem and how it has affected their life. Scores reflect symptom severity and QoL on four domains: gastrointestinal and systemic symptoms, and emotional and social functioning. It has been found to be a reliable (Cronbach's alpha was 0.94) and valid and measure in IBD (Cheung et al., 2000).

**5) Treatment adherence:** *IBD –Medication Taking Behaviour Scale* (MTBS; Morisky et al., 1986)

The MTBS is a four item measure that is used to assess medication adherence in IBD patients over the previous two-weeks; by asking respondents to answer 'yes' or 'no' to a series of questions. It has been found to have good reliability (Cronbach's alpha was 0.61) and validity with this population (Morisky et al., 1986).

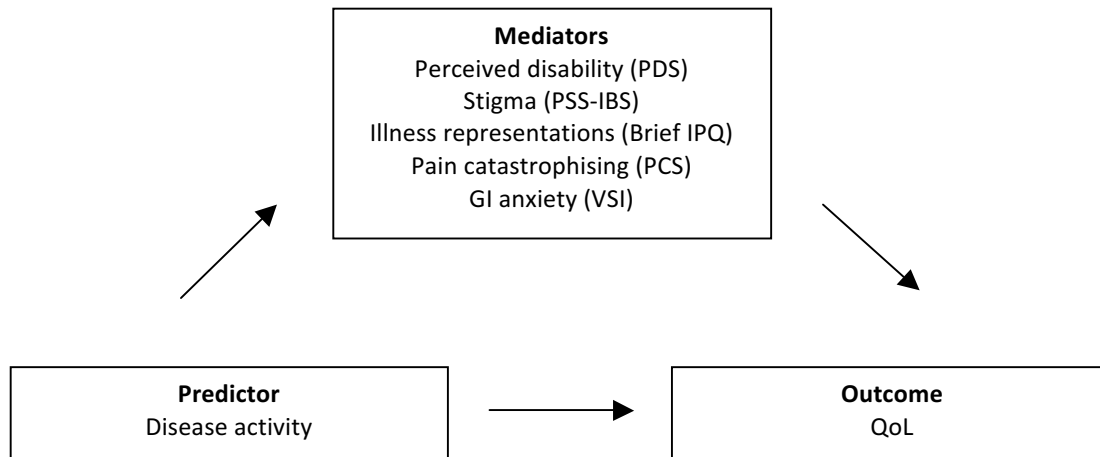
### ***Statistical analysis***

Statistical analyses were completed using SPSS 22.0 for Windows (SPSS Inc., Chicago IL).

An initial exploratory analysis was carried out to ascertain whether the data met the assumptions for parametric analyses. A correlational analysis was then conducted to see if there was an association between the main predictors and outcomes, specifically QoL. This was followed by a mediation analysis to see if psychological distress mediates the effect of disease activity on QoL. The mediation hypothesis was tested using Hayes (2013) SPSS macro for mediation downloadable from Andrew Hayes' website (<http://www.processmacro.org/index.html>, accessed 26<sup>th</sup> June 2017). The proposed mediators were simultaneously to assess for the effect of disease activity on QoL. Enabling assessment of a number of mediators, mediation

models reduce the likelihood of parameter bias as a result of omitting variables (Hayes and Scharkow, 2013) and facilitates establishing the magnitudes of indirect effects associated with the proposed mediators. The mediation model is presented in *Figure 1*.

**Figure 1: Mediation models assessed**



For the subsidiary exploratory analysis the research aim was then addressed using hierarchical multiple regression analyses. The initial plan was to enter predictors in the following order; disease activity was entered first as previous studies have shown this variable to be one of the most important predictors of adjustment to IBD (Graff et al., 2009, Liz et al., 2008). Perceived disability was entered second as a positive relationship between disability and psychological distress has previously been reported in chronic disease (Innamorati et al., 2009). Finally, illness representations, pain catastrophising and GI anxiety were entered into the model simultaneously in order to further establish the relative contribution of these factors on distress (Kiebles et al., 2010; Lix et al., 2008). The exact variables included in the final regression models were informed by the correlation matrix and hence a further model was included in the final regression to establish if treatment adherence was predicted by stigma and/ or GI anxiety.

***Ethical considerations***

A favourable ethical opinion for the study was obtained from the University of Edinburgh School of Health in Social Sciences Ethics Committee (see *Appendix 2*). All participants were provided with an information sheet and were required to give informed consent prior to taking part in the study (see *Appendix 3* and *4* respectively).

## 1.6. Results

### *Descriptive statistics*

Participants consisted of 338 individuals with IBD (N = 283, 83.7% females and N = 55 males, 16.27%). The majority were between 25 – 34 years old (N = 107, 31.7%) and were married or in a domestic partnership (N = 168, 49.7%). Most had a self-reported diagnosis of CD (N = 195, 57.7%) or UC (N = 129, 38.2%). Of the participants, 302 (89.3%) were diagnosed four or more years ago and 150 (44.4%) experienced constantly or often active disease (see *Table 1* for sample characteristics).

**Table 1: Demographic characteristics of the sample**

|                       | Variable                                | Number (N) | Percentage (%) |
|-----------------------|---|------------|----------------|
| <b>Age (years)</b>    | 16 – 17                                 | 2          | .6             |
|                       | 25 – 34                                 | 107        | 31.7           |
|                       | 35 – 44                                 | 75         | 22.2           |
|                       | 45 – 54                                 | 60         | 17.8           |
|                       | 55 – 64                                 | 54         | 16             |
|                       | 55 – 64                                 | 32         | 9.5            |
|                       | 65 – 74                                 | 8          | 2.2            |
| <b>Marital status</b> | Married/ domestic partnership           | 168        | 49.7           |
|                       | Single                                  | 135        | 39.9           |
|                       | Divorced                                | 21         | 6.2            |
|                       | Separated                               | 14         | 4.2            |
| <b>Diagnosis</b>      | CD                                      | 195        | 57.7           |
|                       | UC                                      | 129        | 38.2           |
|                       | 'Other' such as Collagenous Colitis and | 14         | 4.2            |

|                             | Lymphocytic Colitis                           |     |      |
|-----------------------------|---|-----|------|
| <b>Time since diagnosis</b> | < 6 months – 1 year ago                       | 36  | 10.7 |
|                             | > 1 years ago                                 | 302 | 89.3 |
| <b>Disease activity</b>     | Constantly or often active disease            | 150 | 44.4 |
|                             | Sometimes or occasionally active disease      | 125 | 37   |
|                             | Rarely/ in remission/ absence of IBD symptoms | 63  | 18.6 |

### ***Exploratory analysis***

There was no missing data in the dataset as the online questionnaire had a forced completion option. Boxplots were plotted for all outcome variables and screening the data did not reveal any outliers that would have biased the mean or inflated the SD.

Normality was examined using the Kolmogorov-Smirnov test. For IBDQ,  $D(126) = 0.06$ ,  $p < 0.05$ ; PHCS,  $D(126) = 0.07$ ,  $p < 0.05$ ; BIPQ,  $D(126) = 0.8$ ,  $p < 0.05$ ; VSI,  $D(126) = 0.07$ ,  $p < 0.05$ ; VQ Obstruction,  $D(129) = 0.06$ ,  $p < 0.05$  indicating these variables were not normally distributed. However doing a visual inspection of the histograms and the Q-Q plots the data distribution seemed to be normal. As noted by Tabachnick and Fidel (2011), in large samples (100 or more) the Kolmogorov-Smirnov approach tends to be oversensitive and a visual inspection of the data is more appropriate, therefore a decision was made to use the untransformed data for parametric analyses. As a way to deal with potential deviations from normality the bootstrapping function was used which provides a more robust account of the results that makes no assumptions about distributions as recommended by Hayes and Scharkow (2013) for mediation using a bias corrected 95% confidence interval with 5000 bootstrapped samples.

### ***Correlational analysis***

A correlation analysis was carried out to investigate the first aim and identified several statistically significant relationships between the predictors and outcomes, which were in the anticipated direction. Notably, there were significant negative correlations between the illness related cognitions (barring stigma), disease activity and the QoL measure of psychosocial adaptation. Additionally, pain catastrophising,

disease activity, perceived disability and illness representations were not found to be associated with treatment adherence. In addition, more active disease was associated with significant obstruction in engaging in activities. Perceived stigma was only found to be significantly associated with treatment adherence although the strength of this association was small. Both illness representations and gastrointestinal specific anxiety were found to be statistically significantly associated with all adjustment indicators. However, illness representations was not significantly associated with treatment adherence. There was a general negative association between the predictors and progression in activity engagement as well as sense of mastery. For example, higher pain catastrophising was associated with less sense of mastery and progression in activity engagement (see *Table 2* for relationships).

**Table 2: The relationship between potential predictors and outcomes for individuals with IBD**

| Outcome variables                           | Predictor variables    |                      |                  |                      |                  |                         |                               |
|---|------------------------|----------------------|------------------|----------------------|------------------|-------------------------|-------------------------------|
|   |                        | Pain catastrophising | Disease activity | Perceived disability | Perceived stigma | Illness representations | Gastrointestinal (GI) anxiety |
| <b>QoL</b>                                  | Pearson Correlation    | -.40 **              | -.64 **          | -.46 **              | -.06             | -.42 **                 | -.53 **                       |
|   | Pearson Correlation CI | (-.63, -.17)         | (-.81, -.46)     | (-.68, -.21)         | (-.24, .11)      | (-.65, -.15)            | (-.65, -.40)                  |
| <b>Psychological functioning stress</b>     | Pearson Correlation    | .45 **               | .35 **           | .50 **               | .17              | .42 **                  | .32 **                        |
|   | Pearson Correlation CI | (.29, .60)           | (.16, .52)       | (.34, .62)           | (-.01, .35)      | (.26, .56)              | (.14, .51)                    |
| <b>Psychological functioning depression</b> | Pearson Correlation    | .46 **               | .38 **           | .47 **               | .16              | .43 **                  | .44 **                        |
|   | Pearson Correlation CI | (.27, .63)           | (.37, .49)       | (.30, .61)           | (-.01, .34)      | (.27, .57)              | (.28, .58)                    |
| <b>Psychological functioning anxiety</b>    | Pearson Correlation    | .46 **               | .36 **           | .47 **               | .14              | .35 **                  | .39 **                        |
|   | Pearson Correlation CI | (.30, .60)           | (.15, .57)       | (.32, .62)           | (-.07, .33)      | (.19, .50)              | (.25, .54)                    |
| <b>Treatment adherence</b>                  | Pearson Correlation    | -.03                 | .03              | .01                  | .19 *            | -.05                    | -.20                          |
|   | Pearson Correlation CI | (-.02, .15)          | (-.13, .19)      | (-.07, .25)          | (-.36, -.01)     | (-.24, .14)             | (-.38, -.01)                  |
| <b>Mastery</b>                              | Pearson Correlation    | -.38 **              | -.37 **          | -.38 **              | -.43             | -.62 **                 | -.34 **                       |
|   | Pearson Correlation CI | (-.53, -.21)         | (-.54, -.23)     | (-.54, -.22)         | (-.19, .12)      | (-.72, -.52)            | (-.52, -.16)                  |

|  |                        |              |             |              |             |              |              |
|--|------------------------|--------------|-------------|--------------|-------------|--------------|--------------|
| <b>Activity<br/>engagement<br/>progression</b> | Pearson Correlation    | -.18 *       | -.02        | -.26 *       | -.00        | -.21 *       | -.34 **      |
|  | Pearson Correlation CI | (-.36, -.02) | (-.19, .18) | (-.43, -.08) | (-.18, .16) | (-.40, -.03) | (-.48, -.18) |
| <b>Activity<br/>engagement<br/>obstruction</b> | Pearson Correlation    | .51          | .26 **      | .35 **       | .13         | .40 **       | .30 **       |
|  | Pearson Correlation CI | (.34, .64)   | (.07, .42)  | (.18, .49)   | (-.06, .32) | (.23, .55)   | (.10, .48)   |

CI: Confidence Interval (95%), Correlation significant at \*  $p < 0.01$ , \*\*  $p < 0.05$

### ***Mediation effect analysis***

Regression analysis was used to investigate the hypothesis that illness related cognitions mediates the effect of disease activity on QoL. Results indicated that disease activity was a significant predictor of QoL,  $b = -2.52$ ,  $SE = .31$ ,  $p < .001$ . GI anxiety ( $b = -4.56$ ,  $SE = 1.19$ ,  $p < .001$ ), illness representations ( $b = -6.84$ ,  $SE = .70$ ,  $p < .001$ ) and perceived disability ( $b = -8.72$ ,  $SE = 1.47$ ,  $p < .001$ ), but not perceived stigma or pain catastrophising predicted QoL via disease activity.

The results of mediation testing revealed a 95% bootstrap CI of  $-.06$  to  $.71$  for pain catastrophising and of  $-.03$  to  $.33$  for perceived stigma suggesting that no indirect effects were observed.

The results of the mediation model testing revealed a 95% bootstrap CI of  $.09$  to  $1.09$  for GI anxiety suggesting that GI anxiety mediates the relationship between disease activity and QoL. The model accounted for 42.70% of the variance in QoL.

The results of the mediation model testing revealed a 95% bootstrap CI of  $.59$  to  $1.95$  for perceived disability suggesting that GI anxiety mediates the relationship between disease activity and QoL. The model accounted for 95.8% of the variance in QoL.

The results of the mediation model testing revealed a 95% bootstrap CI of  $.36$  to  $2.46$  for illness representations suggesting that illness representations mediates the relationship between disease activity and QoL. The model accounted for 47.3% of the variance in QoL.

### ***Subsidiary exploratory analysis***

#### ***Regression analysis***

A set of hierarchical multiple regression analyses were performed to address the second aim to investigate the amount of variance explained by each predictor on the outcomes of stress, depression, anxiety, QoL, mastery, progression or obstruction in engaging with valued activities and treatment adherence (see *Table 3* for beta values and standard errors).

For stress, the final model predicted 31.4% of the variance and the regression was found to be statistically significant  $F(332, 337) = 30.36, p < 0.001$ . The significant predictors were perceived disability, pain catastrophising, illness representations and GI anxiety. For depression, the final model predicted 35.9% of the variance and was found to be statistically significant  $F(332, 337) = 37.26, p < 0.001$ . The significant predictors were perceived disability, pain catastrophising and illness representations. For anxiety, the final model predicted 31.3% of the variance and was found to be statistically significant  $F(332, 337) = 30.22, p < 0.001$ . The significant predictors were disease activity, perceived disability, illness representations and GI anxiety. For QoL, the final model predicted 52.6% of the variance and the regression was found to be statistically significant  $F(332, 337) = 76.62, p < 0.001$ . The significant predictors were disease activity, pain catastrophising and GI anxiety.

For mastery, the final model predicted 38.4% of the variance and the regression was found to be statistically significant  $F(332, 337) = 41.41, p < 0.001$ . The significant predictors were perceived disability and pain catastrophising. For progression in activity engagement, the final model predicted 13.8% of the variance and the regression was found to be statistically significant  $F(332, 337) = 10.65, p < 0.001$ . The significant predictors were perceived disability and pain catastrophising. For obstruction in activity engagement, the final model predicted 25.5% of the variance and was found to be statistically significant  $F(332, 337) = 22.21, p < 0.001$ . The significant predictors were perceived disability, pain catastrophising and illness representations.

For treatment adherence, only stigma and GI anxiety were included in the model as suggested by the correlation matrix. The model predicted 3.2% of the variance and the regression was found to be statistically significant  $F(332, 337) = 5.57, p < 0.005$ . Stigma but not GI anxiety was found to be a significant predictor of treatment adherence.

**Table 3: Hierarchical regression for adjustment factors in predicting psychological outcomes in IBD**

|               |                         | Stress                 |      |         | Depression              |      |         | Anxiety               |      |         | QoL                       |      |         |
|---------------|-------------------------|------------------------|------|---------|-------------------------|------|---------|-----------------------|------|---------|---------------------------|------|---------|
|               |                         | B                      | SE B | $\beta$ | B                       | SE B | $\beta$ | B                     | SE B | $\beta$ | B                         | SE B | $\beta$ |
| <b>Step 1</b> | <b>Constant</b>         | 13.45<br>(11.65,15.09) | .87  | .05     | 9.05<br>(6.97,11.12)    | 1.05 | .01     | 7.02<br>(5.50,8.36)   | .75  | .03     | 101.88<br>(99.38,104.39)  | 1.29 | .07     |
|               | Disease activity        | .64<br>(.44,.85)       | .11  | .01     | 0.88<br>(.63,1.15)      | .14  | .00     | .63<br>(.45,.86)      | .11  | .01     | -2.26<br>(-2.60,-1.97)    | .16  | -.01    |
| <b>Step 2</b> | <b>Constant</b>         | 10.53<br>(8.86,12.34)  | .88  | .03     | 5.23<br>(-10.43,-1.01)  | 1.05 | .04     | 4.49<br>(3.08,5.88)   | .72  | .01     | 105.74<br>(102.46,108.85) | 1.52 | .05     |
|               | Disease activity        | .34<br>(.12,.56)       | .11  | .01     | .47<br>(.22,.74)        | .14  | .00     | .35<br>(.16,.59)      | .11  | .01     | -1.84<br>(-2.15,-1.55)    | .18  | -.01    |
|               | Perceived disability    | .15<br>(.10,.20)       | .03  | .00     | .20<br>(.15,.25)        | .03  | .00     | .14<br>(.09,.18)      | .02  | .00     | -.21<br>(-.28,-.11)       | .04  | .00     |
| <b>Step 3</b> | <b>Constant</b>         | .91<br>(-4.68,3.25)    | 2.05 | .12     | -5.77<br>(-10.43,-1.01) | 2.45 | .03     | -1.49<br>(-5.10,1.82) | 1.74 | .05     | 120.83<br>(112.82,127.53) | 3.87 | .06     |
|               | Disease activity        | .04<br>(-.18,.27)      | .11  | .00     | .15<br>(-.11,.42)       | .14  | .00     | .17<br>(.03,.39)      | .11  | .00     | -1.56<br>(-1.96,-1.29)    | .17  | .00     |
|               | Perceived disability    | .07<br>(.02,.12)       | .02  | .00     | .12<br>(.06,.17)        | .03  | .00     | .08<br>(.04,.13)      | .02  | .00     | -.12<br>(-.19,.06)        | .03  | .00     |
|               | Pain catastrophising    | .22<br>(.12,.33)       | .05  | .00     | .19<br>(.08,.30)        | .06  | .00     | .05<br>(-.04,.15)     | .05  | -1.80   | -.21<br>(-.39,-.02)       | .09  | .00     |
|               | Illness representations | .14<br>(.06,.21)       | .04  | .00     | .19<br>(.10,.23)        | .05  | .00     | .14<br>(.07,.20)      | .03  | .00     | -.01<br>(-.13,.10)        | .06  | .00     |

|  |            |                  |     |     |                   |     |     |                  |     |     |                     |     |     |
|--|------------|------------------|-----|-----|-------------------|-----|-----|------------------|-----|-----|---------------------|-----|-----|
|  | GI anxiety | .05<br>(.01,.11) | .03 | .00 | .06<br>(-.01,.13) | .03 | .00 | .08<br>(.03,.13) | .03 | .00 | -.18<br>(-.33,-.05) | .08 | .00 |
|--|------------|------------------|-----|-----|-------------------|-----|-----|------------------|-----|-----|---------------------|-----|-----|

|               |                      | Mastery                |      |     | Progression            |      |       | Obstruction           |      |      | Treatment adherence |                     |     |      |
|---------------|----------------------|------------------------|------|-----|------------------------|------|-------|-----------------------|------|------|---------------------|---------------------|-----|------|
|               |                      | B                      | SE B | β   | B                      | SE B | β     | B                     | SE B | β    | B                   | SE B                | β   |      |
| <b>Step 1</b> | <b>Constant</b>      | 18.80<br>(17.76,19.85) | .52  | .01 | 18.31<br>(16.80,19.55) | .72  | -.04  | 11.20<br>(9.76,12.50) | .67  | .01  | <b>Constant</b>     | 3.45<br>(3.00,3.87) | .23 | -.00 |
|               | Disease activity     | -.45<br>(-.58,-.33)    | .06  | .00 | -.34<br>(-.51,-.14)    | .09  | .01   | .40<br>(.24,.55)      | .08  | .00  | Stigma              | .00<br>(-.02,-.04)  | .00 | .00  |
| <b>Step 2</b> | <b>Constant</b>      | 20.53<br>(19.32,21.64) | .56  | .01 | 20.56<br>(18.48,21.79) | .84  | -.05  | 9.06<br>(7.60,10.54)  | .74  | .02  | GI anxiety          | -.01<br>(-.02,.00)  | .01 | .00  |
|               | Disease activity     | -.26<br>(-.39,-.14)    | .07  | .00 | -.12<br>(-.29,.08)     | .10  | .01   | .17<br>(-.00,.34)     | .09  | .00  |                     |                     |     |      |
|               | Perceived disability | -.09<br>(-.12,-.06)    | .16  | .00 | -.10<br>(-.15,-.06)    | .02  | .00   | .11<br>(.08,.15)      | .02  | .00  |                     |                     |     |      |
| <b>Step 3</b> | <b>Constant</b>      | 30.18<br>(27.84,32.81) | 1.24 | .06 | 25.45<br>(21.70,29.38) | 1.98 | .00   | 2.31<br>(-1.18,6.23)  | 1.87 | -.01 |                     |                     |     |      |
|               | Disease activity     | -.07<br>(-.20,.06)     | .07  | .00 | -.03<br>(-.22,.20)     | .11  | .01   | -.04<br>(-.23,.12)    | .09  | -.01 |                     |                     |     |      |
|               | Perceived disability | -.04<br>(-.07,-.01)    | .02  | .00 | -.08<br>(-.12,-.03)    | .02  | -3.72 | .06<br>(.02,.10)      | .02  | .00  |                     |                     |     |      |
|               | Pain catastrophising | -.24<br>(-.31,-.17)    | .03  | .00 | -.12<br>(.22,.02)      | .05  | .00   | .15<br>(.06,.23)      | .04  | .00  |                     |                     |     |      |

|  |                         |                    |     |     |                   |     |     |                   |     |     |
|--|-------------------------|--------------------|-----|-----|-------------------|-----|-----|-------------------|-----|-----|
|  | Illness representations | -.12<br>(-.05,.03) | .02 | .00 | -.01<br>(.08,.06) | .04 | .00 | .12<br>(.06,.18)  | .03 | .00 |
|  | GI anxiety              | -.01<br>(-.04,.03) | .02 | .00 | .00<br>(-.10,.06) | .04 | .00 | .00<br>(-.05,.05) | .04 | .00 |

- Note  $R^2$  for stress = .10 for step 1;  $\Delta R^2 = .09$  for step 2;  $\Delta R^2 = .12$  for step 3
- $R^2$  for depression = .13 for step 1;  $\Delta R^2 = .12$  for step 2;  $\Delta R^2 = .11$  for step 3
- $R^2$  for anxiety = .12 for step 1;  $\Delta R^2 = .01$  for step 2;  $\Delta R^2 = .19$  for step 3
- $R^2$  for QoL = .41 for step 1;  $\Delta R^2 = .06$  for step 2;  $\Delta R^2 = .06$  for step 3
- $R^2$  for mastery = .14 for step 1;  $\Delta R^2 = .09$  for step 2;  $\Delta R^2 = .15$  for step 3
- $R^2$  for progression = .04 for step 1;  $\Delta R^2 = .07$  for step 2;  $\Delta R^2 = .02$  for step 3
- $R^2$  for obstruction = .07 for step 1;  $\Delta R^2 = .09$  for step 2;  $\Delta R^2 = .09$  for step 3

## **1.7. Discussion**

This study set out to provide a better understanding of the role of disease severity and one's thoughts about their illness in terms of potential impact upon adjustment (as measured by mastery and psychosocial outcomes) to IBD. Support was found for the primary hypothesis that disease activity is indirectly associated with QoL, through mediation by GI anxiety, perceived disability and illness representations but not pain catastrophising or perceived stigma. That the three main mediators observed were identified in this study is consistent with previous findings suggesting associations between these variables. However, this study expands our understanding beyond individual-level factors in a single comprehensive model. As such, GI anxiety, perceived disability and illness representations may be maintaining factors for reduced QoL in phases of active disease. These findings go some way to account for how these variables operate together to unify the fragmented literature and further consider the relationship between disease activity and how this is mediated by a number of factors influencing QoL. Therefore, QoL must be considered as part of a comprehensive biopsychosocial approach in treating IBD.

Consistent with findings from a previous study by Kiebles and colleagues (2010), the present study identified several psychological factors in IBD associated with adjustment to diagnosis. Disease activity, perceived disability, pain catastrophising, illness representations and GI anxiety were found to be significant predictors of adjustment in psychosocial functioning, QoL, mastery and activities engagement. Perceived stigma was also found to be a significant predictor of treatment adherence. In addition, from the initial correlational analysis GI anxiety was found to be associated with the outcome variables QoL, psychological functioning, treatment adherence, mastery and activities engagement. Illness representations, pain catastrophising and perceived disability were associated with the outcome variables barring treatment adherence.

Consistent with the findings from the current study, Kiebles and colleagues (2010) found the majority of IBD patients in their sample reported some degree of disability, even when in remission. The current research found that perceived disability was significantly associated with less activity engagement, higher overall psychological distress and poorer QoL as well as mastery. In addition, perceived disability predicted stress, depression, anxiety, mastery activities engagement and QoL. Individuals who have high perceived disability may not feel that they have a sense of control over their health, especially if they are undergoing many invasive medical procedures and are experiencing pain that they are struggling to manage effectively. Therefore, personal control may be an important aspect of psychological functioning and predict outcomes in those with IBD. As such, ones' individual personal meaning of IBD diagnosis, individual illness attributions, attitudes (both internal and external) may affect disease related outcomes and subsequent adjustment to illness.

Kiebles and colleagues (2010) found that abdominal pain and GI visits specifically were associated with perceived disability and stigma was linked to less activity engagement associated with social impairment. In the present study obstruction in activities engagement was predicted by perceived disability, but also pain catastrophising and illness representations. Moreover, engagement in valued activities was predicted by perceived disability and pain catastrophising. Engagement in valued activities has previously been linked to bowel and systemic health, improved social and emotional functioning, less disability, longer time since diagnosis and less emotional representations and negative consequences of illness (Kiebles et al., 2010). These findings add to the research around the importance of engaging in activities in IBD for overall wellbeing and so may be an important intervention target.

Pain catastrophising is widely viewed as a multidimensional construct comprising elements of rumination, magnification and helplessness (Van Damme et al., 2002) and was found to be associated with the adjustment outcomes. Catastrophic thinking in relation to pain may in fact accentuate levels of pain and emotional

distress, and may be a risk factor for chronicity (Forsythe et al., 2008). Martin and colleagues (1996) suggest individuals who score more highly on measures of pain catastrophising experience more severe levels of anxiety and depression than those who do not. In the present study, pain catastrophising was found to be a significant predictor of stress, depression, mastery, activities engagement and QoL. Therefore, it may be worthwhile screening individuals for indicators of pain catastrophising at IBD outpatient clinics. Those with higher scores may be considered at high risk of developing chronicity and may be appropriate for a risk-factor targeted intervention aimed at facilitating recovery and/ or adaptation to living with chronic pain (Smeets et al., 2006).

Disease activity was found to be an important factor in psychosocial adjustment to IBD, and was an important predictor of QoL. It may also be a particularly important with greater consequence for those with a longer-term diagnosis because of the impact of the fluctuating nature of IBD, and because of the accumulation of symptom burden over time. Irvine and colleagues (1994) looked at the trajectory of change over a two-year period to assess if disease activity was an important factor in IBD outcomes. QoL in patients with inactive disease and remission was found to be the same. Patients with fluctuating disease showed improvement in QoL over time, whereas those with active disease did not show any change in QoL over time. Irvine and colleagues (1994) suggest responses to pain were a key factor in determining outcome, more so in individuals with CD compared with UC, and recommend early pharmacological and psychological treatment strategies. However, Irvine and colleagues (2010) study, like many others used primarily a sample with patients with a long-term diagnosis (around four years) and so this may be an area that warrants future research.

It is widely accepted that in order to make sense and respond to receiving a diagnosis, patients form representations of illness, which can subsequently determine coping and ability to control illness (Leventhal and Diefenbach, 1991). In the present study illness representations were found to predict psychological distress and obstruction in engaging in activities. Illness representations may

therefore be an important area for developing greater understanding of the psychological impact of illness as well as for clinicians in aiding explanation of patterns of care seeking and adherence to medications. It may also be a construct to enable development of interventions that facilitate self-management in IBD.

Stigma was not found to be associated with mastery or activities engagement which is in contrast to a study conducted by Taft and colleagues (2009). Taft and colleagues (2009) found that perceived stigma exists among individuals with IBD with deleterious effects and was mainly linked with diagnosis and overall symptom profile as opposed to disease activity. Stigma was associated with poorer outcomes and those at greatest risk were those with more complex symptoms or more frequent flare ups. As such, Taft and colleagues (2009) suggest that anticipation of a flare up may be sufficient in maintaining stigmatisation. It may be that the measure used to assess stigma in this study, the PSS-IBS (Jones et al., 2009) that was developed specifically for those with IBS did not adequately address perceived stigma in the IBD population. Alternatively, individuals with IBD may not feel stigmatised because the disease profile is relatively hidden, and because it is a physical illness people may be more accepting and less likely to label as it is seen as something outside that individuals control. In one study, findings suggested that 27% patients with IBS reported they felt moderately or extremely stigmatised compared to 8% of IBD patients (Taft et al., 2009). This may be because without a clear physical cause, those with IBS feel that their disease is not taken as seriously (Taft et al., 2011). The current study found that treatment adherence was predicted by stigma and not GI anxiety. It may be that perceived stigma among those with IBD may reduce motivation to take medications. In addition, due to the complex nature of IBD medication regimes non adherence due to perceived stigma may also be a way to avoid unplanned medication disclosure.

Although the concept of GI anxiety is relatively new in the IBD literature, the present study provides some preliminary evidence for its importance in the maintenance and exacerbation of the IBD symptom profile. These findings suggest that GI anxiety is an important predictor of QoL in those with IBD and for these reasons may provide an

insight into developing future treatment interventions focussing specifically on the symptom profile of IBD and its relationship to anxiety. The Visceral Sensitivity Index (VSI; Labus et al., 2004) was designed to measure GI anxiety looking at aspects of fear, anxiety and hypervigilance that can accompany misappraisals of GI specific sensations and discomfort. To our knowledge this is the first time that GI specific anxiety in IBD has been linked to poorer QoL in this patient group and so is an important area for further investigation.

### **1.8. Clinical implications**

The current study has provided insight into psychological factors and adjustment indicators from a multi-faceted perspective, which will facilitate advancement of managing IBD from a biopsychosocial point of view. QoL, psychosocial outcomes and activities engagement are clearly important in IBD management, and as highlighted in the current research are influenced by a number of important psychological predictors. Moreover, periods of active disease have been found to be associated with depressive and anxiety symptoms and more frequent and sooner relapses over the lifetime (Mardini et al., 2014; Mittermaier et al., 2004; Persoons et al., 2005). Provision of psychological intervention specific to the needs of people with IBD may improve long-term outcome. For example, management techniques that support active coping as opposed to avoidant strategies especially during periods of active disease (Leslie et al., 2009). Further, perception of health status has found to be an indicator of likelihood of healthcare utilisation (Leslie et al., 2009). Therefore, healthcare providers may see improvement and more appropriate use of healthcare through more fully assessing health related views and responding accordingly. Indeed, development of effective communication skills between health care staff and patients has also shown to be effective in improving adherence to treatment and health outcomes (Stewart, 1995; Trummer et al., 2006).

### **1.9. Limitations**

1) A potential limitation was the research relied on self-report measures that were sometimes retrospective, leading to subjective recall. Self-report may be vulnerable to bias, including under-reporting of symptoms. This may have been compounded by the fact that two of the measures (VQ and VSI) had not been validated for use with the IBD population. However, previous research has also relied on self-reports of disease symptoms and disease activity to characterise IBS activity in those with IBD (Petrak at al., 2001).

2) The present study relied on a convenience sample, which may have introduced a self-selection bias. Cima and colleagues (2007) found that internet use among those with IBD to be as high as 81%, and IBD patients are likely to use the internet as a source of information about their disease. However, Jones and colleagues (2007) found psychological adjustment between individuals recruited from clinical and Internet populations differs in those with gastrointestinal illness, including IBD. Therefore, future studies should incorporate a more equally selected group of participants.

3) The study also used a cross-sectional design, and thus does not account for changes over time. Previous studies have shown that the fluctuating nature of disease activity in IBD has an impact on QoL as well as psychological functioning over time (Lix et al. 2008). The introduction of a control group may have also enabled comparison to exclude other possible predictors of adjustment outcomes.

4) A final limitation relates to findings from a previous study that lower QoL among online patient samples has been previously reported. Jones and colleagues (2007) suggests that this finding may be influenced by disease severity and/ or stigma in IBD (Jones et al., 2007). Given that the current sample are reporting more active disease and greater perceived stigma in relation to lower QoL the findings may reflect this, or that individuals are more likely to report lower QoL through self-report online.

#### **1.10. Future research**

Investigating theoretically relevant mediators linking disease activity and QoL was the primary aim of the study although there are a number of areas for future research that may be explored to further our understanding of QoL in those with IBD. Specifically, the mechanisms by which GI anxiety, perceived disability and illness representations impact on QoL during active phases of disease. Currently the literature focuses on a range of individual factors associated with QoL. A unified model of how these interact together to impact on QoL would aid our understanding of this construct leading to the development of interventions to better this outcome in those with IBD.

In a longitudinal study, Lix and colleagues (2008) demonstrated changes in disease activity mainly affected QoL and psychosocial functioning remained quite stable. However, this study used a sample primarily with patients with a long-term diagnosis. Although this research had intended to compare adjustment in recently versus long-term diagnosed patients, it was not possible due to the small sample size of recently diagnosed participants recruited. One reason why there may have been less recently diagnosed participants is that this group may just be coming to terms with diagnosis during the initial adaptation stage and so may not have been aware or feel that they could contribute due to lack of knowledge. Therefore, although some studies have been carried out with pediatric and adolescent populations (for example, see Mackner et al., 2004; Goodhand et al., 2012), little is still known regarding the impact of illness on the initial adaptation period in recently-diagnosed adults. Added to these gaps in the literature, little is known regarding the initial impact of illness in recently-diagnosed adults' families.

Further scope for future studies relates to the study design; the cross sectional nature of this study allowed for limited assessment of psychological factors and their relationship with adjustment indicators. Future studies should consider a longitudinal design that evaluates the possible impact changes in disease activity and psychological factors over time on adjustment indicators. This will allow for a more robust examination of disease activity and psychological factors in illness adjustment

in IBD through following both recently diagnosed and long-term diagnosed participants over a period of time, for example, for a year at three month intervals.

### **1.11. Conclusions**

The overall findings from this study found support for the primary hypothesis that disease activity is indirectly associated with QoL, through mediation by GI anxiety, perceived disability and illness representations but not pain catastrophising or perceived stigma. Moreover, there exist a range of adjustment indicators that have a significant role in patients with IBD and may be an important risk factor for poorer QoL and psychosocial functioning. Consistent with findings from an original study by Kiebles and colleagues (2010), the present study identified a number of factors in IBD associated with adjustment to diagnosis, in theoretically predictable ways. Disease activity, perceived disability, pain catastrophising, illness representations and GI anxiety were found to be significant predictors of adjustment in psychosocial functioning, QoL, mastery and activities engagement. Stress, depression, anxiety and obstruction in activity engagement were predicted by perceived disability, pain catastrophising and illness representations. QoL was additionally predicted by GI anxiety, and progression in activity engagement by perceived disability and pain catastrophising. Finally, perceived stigma was also found to be a significant predictor of treatment adherence. This study expands our understanding beyond individual-level factors in a single comprehensive model and provides insight into psychological factors and adjustment indicators from a multi-faceted perspective, which will facilitate advancement of managing IBD from a biopsychosocial framework with a view to enable more effective disease management.

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## **Appendix 1: Inflammatory Bowel Diseases submission instructions to authors**

### **SCOPE**

The focus of the journal *Inflammatory Bowel Diseases*<sup>®</sup> is to bring the most current information in the clinical and basic sciences to all physicians caring for patients with inflammatory bowel diseases, and to investigators performing research in inflammatory bowel diseases and related fields. The journal publishes peer-reviewed manuscripts and review articles in basic and clinical sciences, updates on clinical trials, reviews of the current literature, editorials, and other features.

### **ETHICAL/LEGAL CONSIDERATIONS**

A submitted manuscript must be an original contribution not previously published (except as an abstract or preliminary report), must not be under consideration for publication elsewhere, and, if accepted, must not be published elsewhere in similar form, in any language, without the consent of the publisher. Each person listed as an author is expected to have participated in the study to a significant extent. Although the editors and referees make every effort to ensure the validity of published manuscripts, the final responsibility rests with the authors, not with the journal, its editors, or the publisher. All manuscripts must be submitted through the journal's online submission system at <http://www.editorialmanager.com/ibd/>.

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## Appendix 2: Level one ethical approval



SCHOOL of HEALTH IN SOCIAL SCIENCE  
CLINICAL AND HEALTH PSYCHOLOGY

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Angela Seaman  
Trainee Clinical Psychologist  
School of Health in Social Science  
University of Edinburgh

01 July 2015

Dear Angela,

### Application for Level 1 Ethical Approval

**Project Title:** The impact of illness activity and psychosocial factors in the adjustment to IBD. A longitudinal study comparing recently diagnosed and long-term diagnosed patients.

**Academic Supervisor:** Nuno Ferreira

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 16<sup>th</sup> June 2015.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kirsty Gardner  
Administrator  
Clinical Psychology

## **Appendix 3: Participant information sheet**

### **A cross-sectional study investigating the impact of disease-activity and psychosocial factors in the adjustment to Inflammatory Bowel Disease**

#### **Purpose of the study**

The purpose of this study is to investigate the effects of disease activity and psychosocial factors in the progression of adjustment in individuals with Inflammatory Bowel Disease (IBD; either Crohn's Disease or Ulcerative Colitis) This study is being conducted by Angela Seaman, trainee Clinical Psychologist and it's supervised by Dr Nuno Ferreira, Lecturer, at the University of Edinburgh.

#### **What will happen if I take part?**

This study has two parts, please read the information about each study carefully before deciding to participate. You can participate only in study 1 if you wish.

#### **Study 1**

You will complete a questionnaire, which will take 30-40 minutes to complete. You do not have to complete the questionnaire all in one go. You can save it and come back to it in your own time if this is more suitable for you. The questionnaire includes questions about you (e.g. age, gender), your IBD (e.g. disease activity, time since diagnosis), how you are adjusting to IBD, some psychosocial factors that might contribute to this adjustment, and what your Quality of Life is like.

#### **Study 2**

After you complete the first questionnaire, if you indicate that you would be interested in taking part in the second part of the study we will ask for your email address and be in touch again two times (in six months and in a year), to re-complete the same questionnaire The purpose of this study is to see if your responses change over time.

#### **Benefits of this study**

You will be adding to knowledge about IBD and adjustment to the disease. We hope that in the future this knowledge will contribute to the development of interventions that might be

helpful for people with IBD. After we have finished data collection, we can provide you with a brief summary of the main research findings if you request this.

### **Risks or discomforts**

No risks or discomforts are anticipated from taking part in this study. If you feel uncomfortable with a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will NOT be recorded. Taking part or dropping out of the study will not affect your care in any way.

### **Confidentiality**

**Your responses will be kept completely confidential.** We will NOT know your IP address when you respond to the Internet questionnaire. Only the researchers will see your anonymised questionnaire responses and your questionnaire responses will be identified by a special code and no personal information. We will ask you to include an e-mail address after you have completed the Internet questionnaire only if you have shown an interest in participating in the second part of the study. Otherwise your participation will be completely anonymous.

If you take part in Study 2 We will not ask for your name and your e-mail address will not be used during the analysis. The list of e-mail addresses of our participants will be stored electronically in a separate password protected folder. After we have finished data collection and have sent you a copy of the results of the study if requested, we will destroy the list of participants' e-mail addresses.

### **Decision to quit at any time**

Your participation is voluntary; you are free to withdraw your participation from this study at any time. If you do not want to continue, you can simply leave this website. If you do not click on the "submit" button at the end of the survey, your answers and participation will not be recorded. You also may choose to skip any questions that you do not wish to answer.

### **How the findings will be used**

The results of the study will be used for research purposes only. The results from the study will be presented in educational settings and at professional conferences, and the results

might be published in a professional journal in the field of psychology. Because we will ask you about a number of different aspects of your IBD, it is likely that we will use your data to address multiple questions regarding adjustment to IBD.

**Contact information**

If you have any complaints about the way in which this research project has been, or is being conducted, please, contact the primary researcher Miss Angela Seaman, Trainee Clinical Psychologist at the School of Health and Social Sciences of the University of Edinburgh, on:

**Email:** [a.seaman@sms.ed.ac.uk](mailto:a.seaman@sms.ed.ac.uk)

**Address:** School of Health in Social Sciences, Teviot Place, Edinburgh, EH8 9AG

**Who has reviewed the study?**

The study has been reviewed by the University of Edinburgh's Research Ethics Committee.

**Contact for further information**

Dr Nuno Ferreira

Lecturer in Clinical Psychology

University of Edinburgh

Department of Clinical and Health Psychology

School of Health in Social Science

Teviot Place

Edinburgh

EH8 9AG

**Tel:** 0131 650 3898

## Appendix 4: Consent form



Clinical and Health Psychology  
University of Edinburgh  
Medical School  
Teviot Place  
EDINBURGH  
EH8 9AG.

**Tel:** 0131 651 3943

**Fax:** 0131 651 3971

### **A cross-sectional study investigating the impact of disease-activity and psychosocial factors in the adjustment to Inflammatory Bowel Disease**

**Principal Researcher:** Angela Seaman

1. I confirm that I have read and understood the information sheet for the above study and had the opportunity to contact the researchers to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving any reason and without my treatment being affected.

3. In the case of withdrawal I understand that any information collected up to that point can still be used by the researchers

4. I agree to take part in study 1 and I am aware that this involves filling out questionnaires on paper copies.

**Name of Participant**

**Date**

**Signature**

**Researcher**

**Date**

**Signature**

Angela Seaman

**MANY THANKS FOR AGREEING TO TAKE PART IN THIS PART OF THE STUDY.**