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**Governance, participation and avoidance:
everyday public involvement in the Scottish
NHS**

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PhD in Politics

University of Edinburgh

2012

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DECLARATION

26th October 2011

I declare that, except where otherwise indicated, this thesis is entirely my own work, and that no part of it has been submitted for any other degree or professional qualification.

Ellen A. Stewart

Public involvement in health services is an area of policy where ostensibly good intentions appear to repeatedly fail in implementation. Since the late 1990s public involvement in the UK NHS has been subject to frequent reforms, and this has continued in Scotland since devolution. Reformers have criticised mechanisms for being subject to manipulation by managers, parochial in their outlook, and crucially, 'unrepresentative' of the wider public. Academic literature has responded primarily by seeking to 'fix' the problems of public involvement, offering typologies and models of participation intended to apply across a wide range of settings and to the entire 'public'. Taking a different route focused on the complexity of a single case, this thesis explores the multiple meanings and goals contained within the public involvement agenda in Scotland, and argues that these are far-removed from the way that many individual patients seek to influence their health-care in the everyday. In particular this project illuminates the creative and political potential of citizens' interactions with public services.

Research comprises an interpretive case study of the implementation of public involvement policy within one Community Health Partnership in Scotland, and a nested case study of interviews with 'ordinary' young adults in the area. Fieldwork across twelve months included semi-structured interviews with staff, participants, and young adults; observation of public and private meetings of the Community Health Partnership and the Public Partnership Forum; and analysis of local reports and plans for public involvement. Given a low level of awareness or interest in public involvement, interviews with young adults concentrated instead on accounts of using health services. Rather than simply illuminating 'non-participation', the resulting data act as a lens through which public involvement policy can be seen anew.

Public involvement is depicted as an unevenly embedded assemblage of actors and materials pursuing a range of goals, including the strengthening of public influence and the diversification of the public voice. I argue that many current participants in the Public Partnership Forum seek not to change the NHS, but to serve or assist it, and accordingly that their actions can best be understood as work or volunteering, not as activism. Finally, drawing on the reported experiences of my young adult interviewees, I argue that the transition from individual patient to participant is an unlikely one, revealing a range of alternative (oppositional) tactics available to individuals who feel

unhappy with some aspect of their care. I conclude by arguing that NHS staff confront the inherently chimerical nature of participatory projects within public services. By operating without a sense of what amount or degree of participation is 'good enough', public involvement re-interprets my young adult interviewees as apathetic non-participants, and NHS managers and staff as failed engagers. The thesis uncovers the neglected, often-mundane everyday realities of public involvement as both governmental practice and citizen participation. In doing so it troubles the growing literature on contemporary forms of citizen participation and engagement, demonstrating the need for a critical approach to an ostensibly compelling policy agenda.

ACKNOWLEDGEMENTS

First thanks go to my interviewees, who let me into their homes and offices to ask my questions. Staff and members of Rivermouth Public Partnership Forum put up with my presence for the longest by far, and for me it was a great pleasure to know them. The topic of the study held almost no interest for most of my young adult interviewees: the fact that they took part in the study regardless was invaluable.

Many thanks are due to my supervisors – Dr Richard Freeman, Professor Kathryn Backett-Milburn and Professor Andy Thompson – for their support, wisdom and patience throughout my PhD. Many other people at the University of Edinburgh have contributed in different ways over the years. Dr Heather Milne offered invaluable support with the intricacies of the NHS Medical Research Ethics Committee. Insightful, careful and immensely useful comments have come from other PhD students, particularly Corra Boushel. Various manifestations of the Policy & Governance Research Group, and Richard Freeman’s amorphous Materials & Practices Reading Group offered challenges and help. Outwith Edinburgh, discussions with Dr Scott Greer helped me think through many ideas which have made this PhD better.

I am tremendously grateful to Politics & IR for awarding me an ESRC studentship back in 2007. This funding has enabled me to follow my intellectual curiosity in libraries and in the field, and has made for a vastly more interesting and worthwhile PhD than I could have otherwise produced. Further practical and financial support came from the Scottish Primary Care Research Network. Ideas around this project first started puzzling me during my MSc at LSE, and I remain grateful to the Social Policy Department there, where a generous scholarship lured me back into further study, and outstanding teaching sealed my fate.

The support of my friends and family cannot be traced through the arguments of the thesis, but are integral to it existing at all. My parents remain my greatest supporters, and have done an excellent job of not (often) asking why I am still a student. My sister Sarah, editor extraordinaire, helped finalise the thesis. My sister Kirsty willingly submitted to being my first pilot interviewee with good grace and enviable tact, given the evident failings of my schedule and technique. Finally, this thesis would have been impossible without the support, of every imaginable kind, of my partner Jonny.

PUBLIC INVOLVEMENT: AN INTRODUCTION TO THE FIELD

This thesis explores practices of 'public involvement' in local health services in Scotland. I consider these practices to be one example of the citizen participation initiatives which Warren has argued are transforming the nature of contemporary democratic systems (Warren, 2009a, 2009b). However, while Warren (2009a) identifies the administrative roots of such initiatives – and posits these as an explanation for their peculiarly apolitical image – in the case of health services in the UK, this realm of activity has been driven by policy makers (Forster & Gabe, 2008; Klein, 2010). While implementation (with varying degrees of discretion) belongs to administrators, in this case increased citizen participation in public services has been promoted by elected politicians. While the disciplines of political science and social policy offer established critiques of the way in which political processes generate policy (with policy conventionally understood as a product of politics), in this thesis this is inverted to understand the political products of public involvement policy. By filling a perceived political vacuum at the local level of the NHS (Klein & New, 1998), these policies have generated new political terrain, and this thesis is therefore simultaneously an examination of policy implementation, and of grassroots political action in created “invited spaces” (Gaventa, 2006).

Concerns about the public accountability of the NHS can be traced back to its creation (Hunter & Harrison, 1997). In the early days of the British NHS Bevan famously declared: “The Minister of Health will be whipping-boy for the Health Service in Parliament. Every time a maid kicks over a bucket of slops in a ward an agonised wail will go through Whitehall” (quoted in Foot, 1973, p. 192). Since the 1970s, health policy has been concerned to establish other avenues for redress and influence than direct control by Central Government. This is, however, an area of health policy which has repeatedly proved problematic for policy-makers: Klein describes the reform of public involvement policy as a “stutteringly inconsistent process” (Klein, 2010, p. 234). Proposed measures have included repeated reforms of the local structures of public involvement, reforms of complaints systems, increasing local authority oversight of NHS services and, in Scotland, the direct election of members of Health Boards. What is

remarkable is the consistency of the criticisms and dilemmas which have plagued the various models of involvement over time (Carlyle, 2008; Learmonth, Martin, & Warwick, 2009).

PUBLIC INVOLVEMENT IN THE SCOTTISH NHS

While the twists and turns of public involvement policy in the NHS in England have been subject to extensive analysis and critique (Alborz, Wilkin, & Smith, 2002; W. Anderson, Florin, Gillam, & Mountford, 2002; Andersson, Tritter, & Wilson, 2006; Baggott, 2005; Callaghan & Wistow, 2006; Calman, 1996; Davies, Wetherell, & Barnett, 2006; Entwistle, 2009; Farrell, 2004; Klein & Lewis, 1976), this is not true of reforms which have taken place in Scotland since devolution. At the time of writing only one peer-reviewed article takes Scottish public involvement policy as its central topic (Anton, McKee, Harrison, & Farrar, 2007) and the growing literature on Scottish health policy more broadly has tended to concentrate on the more attention-grabbing 'flagship' policies such as free prescriptions (Greer, 2004, 2008; Keating, 2010; McGarvey & Cairney, 2008; Tannahill, 2005).¹ There are several notable pieces of 'grey' research commissioned by the Scottish Government and carried out by small research consultancies (FMR Research, 2008; Scottish Councils Foundation & McCormick-McDowell, 2008). These add useful detail but are (appropriately) focused on making practical recommendations within the bounds of current policy. Given the lack of existing analysis of public involvement within Scottish health policy, this chapter will firstly offer a brief account of what devolution has meant for Scottish health policy, and then set out the reasons why Scotland is an interesting case study for an analysis of public involvement policy. Finally, I will outline the structure of this thesis.

In 1999, health policy was one of the areas devolved to the new (or reconvened) Scottish Parliament. Health policy in Scotland had largely replicated that in England

¹ One public involvement measure, the direct election of non-executive members of Health Boards, seems to be a contender for the ranks of 'flagship' Scottish policies Keating, M. (2010). *The government of Scotland: public policy making after devolution* (2nd ed. ed.). Edinburgh: Edinburgh University Press., but at the the time of writing, it is unclear whether the policy will be implemented.

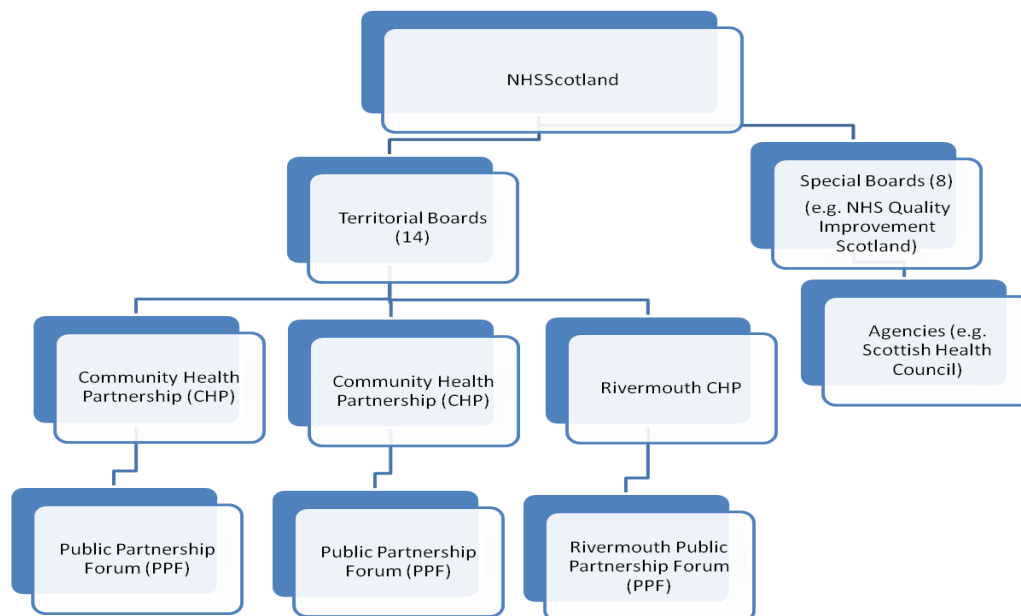
since the creation of the NHS: “For its first fifty years ... the nation in the NHS was Britain” (Greer, 2004, p. 29). This distinguishes health from areas such as education and criminal justice policy, where the separate legal and education systems gave the Scottish Office considerable scope to shape a distinctive approach long before devolution (see for example McAra, 2008; McPherson & Raab, 1988). Limiting this new-found scope for distinctively ‘Scottish’ health policy, is the continued financial dependence of Scotland on Westminster, with the Chancellor of the Exchequer holding the purse-strings for block grant funding (R. Parry, 2002). A number of other issues, for example remuneration of health service employees and professional regulation, continue to be decided on a UK-wide basis (Greer & Trench, 2010). Nonetheless, Scottish devolution was the culmination of a long process of contestation and debate, and the distinctive policy preferences which were part of the political case for reform (Nottingham, 2000) have been self-consciously incorporated into agendas since (Harrington et al., 2009; Tannahill, 2005). Even while Labour was in Government at Westminster and leading a coalition with the Liberal Democrats at Holyrood, policy was required to:

“be distinctively Scottish, in that it demonstrates the benefits of devolution itself; it must be capable of developing along lines that do not immediately solidify into zero sum confrontation with London over powers or financial resources, and thus empower the nationalist opposition; and it must be seen to be at least no less effective than what has gone before.” (Nottingham, 2000, p. 174)

Twelve years and two administrations later, the Scottish NHS looks profoundly different from the system south of the border. As figure 1 shows, 14 territorial Boards plan and deliver all health services for a given geographical area. Each Board has a number of Community Health Partnerships, organisations set up in 2004 to “provide certain community-based health services, bridge the gap between primary and secondary healthcare services, and improve joint working between health and social care” (Audit Scotland, 2011, p. 7). Additionally, CHPs were seen as the key facilitator of public involvement (Scottish Executive, 2004), and each must have a Public Partnership Forum. While there is scepticism about the degree to which these structural differences translate into different entitlements and experiences for citizens (Mooney & Poole, 2004), or challenge the dominant narratives which limit health policy innovation (K. E. Smith et al., 2009), on the simplest level the structure of the NHS is dramatically altered. The purchaser-provider split has been dissolved, and unified territorial Health Boards

now have responsibility for health planning and service provision across Scotland. As the English NHS is encouraged to open up to private providers, with patient choice and competition seen by successive administrations as the most effective route to high quality services, Scotland has broadly rejected this route (Greer, 2004). While academic attention has focused on a set of ‘flagship’ policies (Tannahill, 2005), more subtle but far-reaching reforms have transformed the organisational maps of the NHS in Scotland to the point where the idea of ‘a’ UK NHS, or indeed, ‘British health policy’ holds little relevance. Accordingly, there is a need for academic analysis of emerging Scottish health policy in its own right, and not merely as an interesting experiment in policy divergence under devolution.

Figure 1: structure of NHS in Scotland



It is in this context that I identify Scotland as an inherently interesting (and not merely convenient) case for a study of public involvement. The conventional policy terminology of involvement in Scotland is ‘Patient Focus, Public Involvement’ (PFPI) (Scottish Executive, 2001); a subtly different phrasing from the English ‘Patient and Public Involvement’ (PPI). While the extent to which this indicates a stronger commitment to collective, as opposed to individual (Forster & Gabe, 2008) forms of involvement is unclear, it does allow issues of patient-centred care to be kept reasonably distinct from discussions of how local communities hold services to account. In many ways, the development of Scotland’s public involvement structures until 2007 mirrored those in

the English NHS. While New Labour at Westminster abolished Community Health Councils and created Public and Patient Involvement Forums (along with their national body, the Commission for Public and Patient Involvement in Health), the Labour-Liberal Democrat coalition in Scotland abolished Local Health Councils and created Public Partnership Forums (along with a less independent national monitoring body for involvement, the Scottish Health Council). However, while Westminster then proceeded to abolish PPI Forums and the CPPIH in favour of more networked, diffuse organisations (Local Involvement Networks), the SNP taking power as a minority Government in May 2007 marked a break in these broadly parallel trajectories.

Both the NHS generally, and public involvement specifically, were quickly established as priorities. In June 2007, Health Secretary Nicola Sturgeon reversed the decision to close two Accident and Emergency departments and announced a presumption against centralisation of health services, arguing that “The two Boards did not in my view give sufficient weight to the concerns expressed by local people” (quoted in BBC News Online, 2007). The SNP’s major health White Paper *Better Health Better Care* (The Scottish Government, 2007) contained a number of novel proposals for public involvement, alongside a commitment to retain the basic structure of Public Partnership Forums and the Scottish Health Council. It included a proposal for directly elected Health Boards, and an annual NHS ‘Ownership Report’ for every household in Scotland. However, as a minority Government until May 2011, the SNP struggled to move forward with much of their agenda, and relatively few of these proposals had come to fruition by the time of my fieldwork in 2009/10. The commitment to directly elected Health Boards was reduced to a pilot scheme in the face of extensive opposition (Greer, Donnelly, Wilson, & Stewart, 2011). The Charter of Mutual Rights has become a Charter of Patient Rights and Responsibilities, contained within a Patients’ Rights Bill passed in February 2011. The Ownership Report has, like several Patients’ Charters in the past (Forster & Gabe, 2008), become essentially a guide to accessing services. While a new ‘Participation Standard’ was published in 2010 (Scottish Health Council, 2010), it is yet to be integrated into the national system of performance management. Proposals to strengthen Public Partnership Forums have not materialised. While they remain in place their role has shifted subtly from being “the main way” (Scottish Executive, 2004, p. 4) the NHS involves the public to being one of “many different ways” of “listening and responding” (Scottish Health Council, 2010, p. 16). At least from a structural perspective, on-the-ground public involvement does not appear to be transformed by the SNP

reforms, particularly in Boards which are not piloting elections. Thus my fieldwork was largely concerned with the reforms of earlier Executives: the functioning of Public Partnership Forums, the role of the Scottish Health Council, and, although this was rarely mentioned in fieldwork, the statutory duty for Boards to involve the public.

I find this case of public involvement interesting for two specific reasons. Firstly, the fact of devolution adds a novel dimension to the study. 'Public involvement' taps into long-standing worries about the NHS (Klein & Lewis, 1976; Klein & New, 1998) but became a reasonably coherent policy agenda under the New Labour government from 1997 onwards (Forster & Gabe, 2008). Since devolution, the Scottish approach has contained subtle differences of purpose and (to a lesser degree) terminology from the English baseline, and under the SNP it has shifted significantly further. Initial plans for a comparative study were rejected on the grounds that it was unfeasible to conduct interpretive fieldwork in two very different locations within the time constraints of a PhD. However, it is near impossible to study Scottish policy without an awareness of the context of the UK, and specifically the English approach. In demonstrating a concern with partnership and public co-ownership for the NHS, Scotland's model of public involvement offers an alternative approach to the English model, and reveals the range of possible emphases within what often appears a very unitary agenda. Secondly, the particular characteristics of the Scottish NHS structure make it a valuable case study. Unified territorial Boards increase the potential for concerted system action, which is difficult under a purchaser-provider split. If organisations are more powerful and centralised it is both more important, and simpler (if not necessarily easier) to hold them to account. Furthermore, the very limited degree of patient choice within the Scottish system should (by an economic logic) strengthen public involvement as a mechanism of 'voice' (Hirschman, 1970). In theory, without the option of attending an alternative provider, the public should rally round to improve their local facilities.

Having argued that public involvement policy in Scotland is an interesting case, it is necessary to explain how and why my approach has diverged from most of the existing studies of related policy elsewhere (which will be outlined in chapter 2). Making use of the freedom of PhD research, my research design evolved significantly in the field. The research design was initially conceived in two strands: a scene-setting exercise to map the local structures of public involvement, and a nested case study of young adults'

'experiences and perceptions', developed to shed light on the preferences of groups who remain problematically under-represented within both research and practice in public involvement. In the field, this design evolved in response to challenges and opportunities. A map of public involvement proved inadequate to represent the contingency and flexibility of local practice. In the work of the Public Partnership Forum there was more of interest, and less on which people agreed, than I had anticipated. Accordingly, this strand of the research grew in scope and significance. In contrast, my research with young adults proved difficult because of a *lack* of 'relevant' content. While accounts of health service use were easily forthcoming, 'perceptions' of public involvement were not merely difficult to prompt but absent. The solution, reached after much puzzling, was to reconceive of my young adult interviewees' accounts – including ostensibly irrelevant acts of non-participatory agency – not as examples of non-participation, but as a lens through which to view public involvement policy differently. The difficulty of combining these two strands of fieldwork – conducted in the same towns and villages in the same months – into one study becomes part of my findings. I believe that what results, although cumbersome when compared to the streamlined design of my initial research design, offers a reasonably novel perspective on the topic. I hope that it plays a part in "enabling different questions to be asked" (N. Rose, 1999, p. 277).

STRUCTURE OF THE THESIS

In chapter 2 I begin by reviewing the literature on public involvement in health. Developing Harrison, Milewa, and Dowsell's (2002) 'three literatures' of involvement, I propose that we understand involvement as a topic caught between three distinct sets of concerns: the democratic, the managerial, and the emancipatory. I present 'public involvement' as an empty signifier, a label which is functionally underspecified, allowing the peaceful, though problematic, co-existence of multiple approaches to the topic. Within this literature I point to the prevalence of typologies which rank 'levels' of involvement by the degree to which they empower 'the public'. These typologies allow disagreements over who should be empowered and why to be unresolved and at times unarticulated. Over time, reformulations of these typologies have simplified and blunted Arnstein's (1969) original, provocative 'ladder of participation', removing the highly critical rungs of 'therapy', 'manipulation' and 'citizen control'. Typologies have become advisory, not critical, and most recently influential commentators have argued that even

the presence of ranking is excessive, preferring a more inclusive 'mosaic' of involvement (Tritter & McCallum, 2006).

Having highlighted the weaknesses of the conceptual models that have founded this literature, chapter 2 turns to review the more helpful empirical findings which have been generated. These can be divided into research on specific instances of public involvement and more general assessments of public involvement. The literature on specific instances of involvement contains an enduring preoccupation with, and consistent evidence of, the minimal 'impact' of involvement. This includes Harrison and Mort's (1998) influential critique of public involvement as a "technology of legitimisation". I propose that this analysis (stories of failure) has come to dominate the literature to an unhelpful extent. Secondly, chapter 2 discusses the growing number of studies which seek to analyse public involvement in general and/or to ask members of the public about their preferences for involvement. These studies have consistently shown public preferences for a fairly minimal model of involvement, described in one study as 'accountable consultation' (Litva, Canvin, Shepherd, Jacoby, & Gabbay, 2009). Accordingly within the literature we can ascertain a gap in perception: studies of specific mechanisms consistently find that the public is inadequately empowered, while studies of the public consistently suggest that 'the public' does not subscribe to "citizen control" (Arnstein, 1969) as a goal. Finally, in an effort to get beyond this stalemate, chapter 2 seeks to locate public involvement within the broader insights of social science research on participation and governance.

Chapter 3 presents the design for the empirical research project at the heart of this thesis; an interpretive case study of public involvement practice in a Community Health Partnership in Scotland which I call Rivermouth². In doing so, it considers the varied meanings and purposes of claims to an 'interpretive approach', and sets out the ways in which this has been a useful label for the development of this project. I go on to reflect on the methods used in the study: observation, documentary analysis and semi-structured interviewing. This chapter becomes, to a significant extent, the story of the way in which this study developed and changed in the field. Although it is, for form's sake, presented after chapter 2, my experiences in the field changed not just my

² Names of projects and interviewees have also been changed to protect anonymity.

approach to researching involvement but my reading of the existing literature on the topic. A strictly chronological approach would, therefore, locate this chapter first, as an account of the intellectual process of this research.

Chapters 4, 5 and 6 present my findings on three different groups of actors separately. Chapter 4 describes the way national policy is translated at the local level in Rivermouth. I use the analytic concept of 'assemblage' to describe the shifting set of actors and technologies which constitute the on-the-ground practice of public involvement. Chapter 5 presents data from a year of observing and interviewing the local Public Partnership Forum, a statutory body which policy documents decree to be the "main mechanism" of involvement in Community Health Partnerships (Scottish Executive, 2004). Here, I identify the very different ways in which members described their roles and their motivations for joining the Forum: as volunteers, as consultants, or as challengers. Crucially, in both interviews and observation of meetings I found the overwhelming 'mode' of membership was one of volunteering, with little interest in changing the NHS, and discomfort at the suggestion that members might have pre-defined agendas to pursue. Chapter 6 presents findings from interviews with young adults living in Rivermouth. These interviews, full of uncertainty, silence and shrugs, while ostensibly less revealing than other sections of the research, functioned as a lens through which the policy and practice of public involvement could be seen anew. Reluctant to conclude simply that my interviewees were 'disengaged', I listened instead to accounts of alternative avenues of agency, which I consider as examples of avoidance and everyday creativity (de Certeau, 1984).

Chapter 7 draws together my empirical findings with insights from my review of existing literature. I attempt to re-evaluate what I term the 'who' and 'what' questions of public involvement (who are the public, and what is involvement?), before offering an extended theoretical discussion of public involvement as a terrain of governmental activity, and of the "quieter politics of everyday life in the welfare state" (Soss, 2000, p. 1). I conclude by offering the idea of participation (more specifically, participatory initiatives in public administration) as chimera; positing that the insatiable nature of such projects renders them inherently unsatisfactory for practitioners, participants and analysts. Finally, chapter 8 moves back from the theoretical to the applied, offering some modest recommendations for future policy-making and research in this area.

2. LITERATURE REVIEW

INTRODUCTION

This chapter seeks to offer an account of the current state of knowledge in the area of public involvement in health. In keeping with my broader approach, this review is interpretive. As Greenhalgh et al (2005, p. 427) state:

“Whereas a technical model of systematic review holds that there is a body of research ‘out there’ ready to be discovered, an interpretive model acknowledges that picking out a series of story threads from a heterogeneous and unbounded mass of literature involves choices that are irrevocably subjective and negotiable”.

Bazerman argues that because literature is not codified into a broadly accepted canon, the task of the political scientist writing a literature review is to “reassemble, reinterpret, and discuss anew wide ranges of the literature, dating back into the discipline’s history” (Bazerman, 1988, p. 283). My aim is to do this for the extensive literature that has sprung up around the topic of public involvement in health services.

Accordingly, this chapter divides into two sections. In the first I demarcate and discuss what I have assembled and labelled as the literature on public involvement in health services. I begin by describing the method by which I searched, categorised and analysed the academic literature, before going on to discuss the empirical findings which have emerged from the last decade of research on involvement. I move on to critique some recurring themes within the literature, and highlight problems in the conceptual frameworks which structure academic analysis of involvement. In the second section I argue for the incorporation of broader insights of the social science canon on participation and governance into studies of public involvement. To illustrate the potential gains, I review a selection of key studies: firstly work on civic participation, and secondly, work on government-initiated participatory initiatives.

A REVIEW OF PUBLIC INVOLVEMENT IN HEALTH

METHODOLOGY FOR REVIEW

Given the breadth of literature which touches on these issues, it is worth setting out some parameters for this review. I have restricted discussion to a) the development of 'public involvement' mechanisms for collective accountability and responsiveness within b) health services. This excludes mechanisms of public involvement which exist within social insurance systems, such as the election of Board members to sickness funds in Germany (Haarmann, Klenk, & Weyrauch, 2010). Limiting the review to collective mechanisms rules out discussions of involvement within individual treatment decisions (S. Collins, Britten, Ruusuvoori, & Thompson, 2007; Thompson, 2007). Although later in this thesis I will argue for a stronger linking of individual experience and public involvement, the issues surrounding involvement within the medical encounter are distinct from those present in involvement within a healthcare organisation. The specification of health services excludes involvement in health services research (Oliver et al., 2008; Tritter, 2009). Although there is an extensive literature on public involvement in other public services, and in community planning more generally, it is excluded from the first section of this chapter, except where it is repeatedly cited within the health literature. Key examples of this are Arnstein (1969) on urban planning and articles by Rowe and Frewer (2004, 2005) on science and technology. These parameters allow me to thoroughly discuss a manageable number of studies in this section, before drawing on wider insights in the second section of the chapter.

The review began using a similar approach to that described by Tenbenschel (2010) below. Combinations of search terms were inputted into ISI Web of Knowledge and Google Scholar, citations were downloaded to a master list, and each source was then read for relevance, including references to other material which were then added to the master list. The master list of sources was then inputted into a matrix documenting the central concept, its definition, the evidence/data on which the article was based, and the key conclusions of the study. This section is an attempt to be transparent about the way this review was conducted, acknowledging Bazerman's (1988) point that social scientific literature reviews involve a significant amount of researcher initiative. Given the instability of terminology in this field (of which more later) this was a more organic

process than that implied by 'systematic reviews' such as Crawford et al (2002). As Greenhalgh et al (2005, p. 418) discuss with reference to their review of innovative technologies in health-care, inclusion criteria struggle to accommodate the "fuzzier and contested definitions" which are present in many social science studies. I concur with Hammersley that systematic reviews tend to prioritise positivistic approaches to research and, following Polanyi (1967), that despite the ambitions of systematic reviewing, all science "necessarily relies on personal or tacit knowledge" (Hammersley, 2001, p. 545). This is, accordingly, a narrative review of the literature. However, I do not understand this as a second-place alternative to the preferred option of systematic review (Hammersley, 2001), but as the appropriate strategy for this project.

EMPIRICAL EVIDENCE

This section will discuss empirical studies of public involvement in health, seeking to draw together current knowledge on the topic. This is an expansive literature, which has had at least two major periods of popularity; firstly, in the radical politics of the 1960s and 1970s, and then again in the very different era of what has been described as the New Public Governance (Osborne, 2006). This review will acknowledge these radical roots while concentrating on more recent literature. Political science has not been the primary investigator of policy and practice in this area, which has been studied by researchers from the disciplines of social policy, medical sociology, public health, health services and management. In health services research, studies have been characteristically inter-disciplinary and heavily applied. More recently has come the appointment of Professors of Public and Patient Involvement (at London South Bank University and then at the University of Warwick), suggesting the existence of a distinctive sub-discipline. Empirical studies are accompanied by a wide range of other articles: editorials (Harrison, et al., 2002; Tenbensen, 2010); opinion pieces (Cayton, 2004; Klein, 2004); and responses to policy developments (Cayton, 2004; Florin & Dixon, 2004; Forster & Gabe, 2008; Klein, 2004; Milewa, 2004; Pickard, 1997; Sang, 2004). Other articles are based on literature reviews which make variable claims to being 'systematic' (I. Brown, 1999; Crawford, et al., 2002). This is also an area notable for the presence of considerable grey literature, from organisations such as *Involve*, the *Picker Institute* and the *King's Fund*. Some of this reports rigorous analysis grounded in transparently-reported research (W. Anderson, et al., 2002), while others exist primarily to make a case for public involvement as necessary and beneficial (Andersson, et al.,

2006). Drawing on Kuhn’s (1962) account of ‘normal science’, I argue that public involvement has become a field dominated by researchers operating (as all researchers tend to) “to a set of rules and standards which are considered self-evident by those working in a particular field, but which are not universally accepted” (Greenhalgh, et al., 2005, p. 418). This section endeavours to elaborate some of the recurring themes which characterise this literature. Firstly, I will discuss case studies of actual public involvement exercises. I will follow this by considering the small but growing number of studies which consider public opinion or preferences for involvement *in general* as opposed to in the context of a specific exercise.

Table 1: studies of implemented public involvement mechanisms

Study	Mechanism(s) studied	Methods used
Alborz, Wilkin, and Smith (2002)	Primary Care Groups and Trusts’ actions to involve and consult local communities.	Survey of Primary Care Trusts (telephone) and survey of lay representatives and Community Health Councils (postal).
Anderson, Florin, Gillam and Mountford (2002)	Mechanisms of involvement in six London Primary Care Groups and Trusts.	Case studies: participant observation; interviews with stakeholders (mostly staff).
Anderson, Shepherd, Salisbury (2006)	Two primary care initiatives based around Healthy Living Centres.	Two case studies: interviews and focus groups with staff and involved citizens (on a scale of high, medium and low involvement).
Anton, McKee, Harrison and Farrar (2007)	General Scottish public involvement policy. Single example of service redesign.	Interviews with ‘stakeholders’ in Scottish policy-making community; Case study of service redesign: interviews with local ‘stakeholders’.
Callaghan and Wistow (2006)	‘Approaches to involvement’ in two Primary Care Groups.	Case studies: observation of meetings (Board and public); interviews with Board members (including lay members); documentary analysis.
Conway, Cranshaw, and Bunton (2007)	Health Action Zone.	Case study: interviews with staff.
Davies, Wetherell and Barnett (2006)	NICE Citizens Council	Ethnographic research: observation and video-recordings of meetings; documentary analysis; interviews with staff and public members of Citizens Council.

Harrison and Mort (1998)	Health panels, run by Health Authorities.	Survey of Health Authorities.
Lightfoot & Sloper (2006)	Involvement of young people with chronic illness or disability in health service development.	Individual and group interviews with staff and participants.
McIver (1999)	Public participation efforts of Health Authorities and Health Boards.	Postal survey.
Martin (2008b)	User involvement in pilot cancer-genetics projects.	Interviews with involved service users, and staff; participant observation at events and meetings; documentary analysis of plans and reports.
Milewa, Dowsell, Harrison (2002)	Attitudes and responses to Patient and Public Involvement in Primary Care Groups and Primary Care Trusts.	Interviews with key informants (snowballed): staff, lay representatives, individuals from voluntary and community groups.
Milewa, Harrison, Ahmad, & Tovey (2002)	Primary Care Groups' efforts at patient and public involvement	Telephone interviews with spokespeople for 167 Primary Care Groups.
Milewa, Valentine and Calnan (1999)	Views of Health Authority managers on community participation.	Interviews with Health Authority managers.
Murie and Douglas-Scott (2004)	Initiatives within one GP practice over 5 years including: fundraising walks, quarterly public meetings, Patient Participation Group, consultation on service planning and redesign.	Experience as practitioners.
O'Keefe and Hogg (1999)	Capacity-building project to engage specific group of service users.	Practitioners' experience of project evaluation.

Table 1 lists studies which consider public involvement in health by focusing on implemented examples of public involvement since 1998. While some of the studies are from outside the UK, this date allows me to focus on research conducted in and since the New Labour era. Studies are overwhelmingly concerned with staff and organisational perspectives, and the public voices within these studies come from 'the involved'; for example, lay members on committees. Empirical studies demonstrate a range of approaches to studying public involvement, with case studies of local initiatives (found to comprise 74% of the available literature by one systematic review (Crawford, et al., 2002)) and surveys of multiple organisations the most popular approaches. Most studies are preoccupied with the success or failure of public involvement activities and

the literature is more often reviewed to yield meta-narratives of how to 'do' public involvement (Abelson & Gauvin, 2006), than to offer a critical analysis of it. In particular, problems are traced to two linked dilemmas within involvement practice. One is related to questions of impact, and the other, to questions of representation. Neither is uncontroversial.

Entwistle (2009, p. 1) discusses the risks of demands for impact from involvement, particularly around instrumentalising participation, but concludes "the notion of participation makes little sense if potential for influence is entirely lacking". A few studies offer sympathetic interpretations of a lack of influence. In Anderson et al's (2002, p. 61) study, many of the weaknesses of public involvement exercises are attributed to a kind of complacency born of time constraints: "Those who accepted things as they were tended to focus their energies on the mechanisms of involvement rather than the mechanisms of change – they assumed the latter were in reasonable working order". Callaghan and Wistow's case studies demonstrate two different approaches to public involvement – a dialogue versus a snapshot – but the authors find that both are underpinned by a 'scientific rationalism' by which "both boards gave primacy to their own 'expert' knowledge" (Callaghan & Wistow, 2006, p. 2299). Some studies highlight the presence of individuals within organisations who promote and support involvement; Harrison and Mort (1998) describe these as "participation entrepreneurs". In other cases, individuals operate as a conduit for public views; Anderson et al highlight the example of a diabetes support nurse who "completely ignored the formal processes of decision-making and learning in the PCG but sustained a shared process of learning through her informal network of professional contacts" (W. Anderson, et al., 2002, p. 61).

However, as Crawford, Rutter, and Thelwall's systematic review states, multiple papers conclude that staff are the crucial obstacle to the impact of involvement (Crawford, Rutter, & Thelwall, 2003). One author notes within the literature "a widely observed reluctance on the part of health professionals and managers to engage with the public and put into practice the outputs of public-involvement processes" (Martin, 2008b, p. 1757). Harrison and Mort (1998) coin the term "technology of legitimation" and offer an account of the way in which public involvement efforts can be used by manipulative managers:

“the simultaneous construction of user groups’ legitimacy by the expression of positive views about them, and its deconstruction by reference to their unrepresentativeness and/or unsatisfactoriness as formal organisations constitutes a device by which whatever stance officials might take in respect of user group preferences or involvement on particular issues could be justified.” (Harrison & Mort, 1998, p. 66)

In this interpretation, dilemmas of impact (attributed to staff members’ interference) are closely linked with dilemmas of representation.

Representation is an enduring dilemma within the public involvement literature. Harrison and Mort (1998) point to the uncertain, unstable legitimacy of user groups, and to the non-binding, informal manner in which they feed into decision-making. In their study of NICE’s Citizens Council, Davies, Wetherell, and Barnett identified a move away from the authority of the Council – a deliberative body founded and recruited at considerable expense – towards public opinion surveys and focus groups (Davies, et al., 2006). Acknowledging that many studies identify that “health professionals ... keen to retain control over decision-making, undermine the legitimacy of involved members of the public, in particular by questioning their representativeness” (Martin, 2008b, p. 1757), Martin places the question of representativeness at the centre of his paper. However unlike analyses which identify a zero-sum power battle as the cause of failures, he points to ambiguity in policy objectives around involvement as creating the tension between staff and public representatives. Reconfirming the linkages of the two dilemmas I have outlined, in later co-authored work, Martin argues that demands for impact or demonstrable influence should be restricted so that involvement mechanisms do not prevent a more representative sample of the population from taking part (Learmonth, et al., 2009). Alternatively, one study looking at young people in hospitals as an example of an under-involved group explicitly argues for a ‘listening culture’, whereby issues can be raised informally, rather than formal projects of involvement (Lightfoot & Sloper, 2006). Young people, and other groups perceived as ‘hard-to-reach’, are often seen as better ‘involved’ through dialogue with trusted professionals, than roles within formal mechanisms (Lightfoot & Sloper, 2006; Macpherson, 2008).

This concern with engaging ‘ordinary’ (Learmonth, et al., 2009; Martin, 2008a) members of the public (implicitly those who do not take part in involvement) has prompted a

cluster of studies seeking public views on involvement in general (see table 2). These studies include members of the public with a range of experiences, from the ‘unengaged’ to experienced participants. In seeking to speak for such a broad group, these papers are prone to broad conclusions which border on banal. Litva, Canvin, Shepherd, Jacoby, and Gabbay's article states simply: “The public has much to contribute, especially at the system and programme levels, to supplement the inputs of health-care professionals” (Litva et al., 2002, p. 1825).

Table 2: studies of public perspectives on involvement in general

Study	Country	Context	Method(s) used
Abelson, Forest, Eyles, Casebeer, MacKean (2004)	Canada	Revising guidance for design of public involvement processes.	Focus groups with experienced citizens.
Litva, Canvin, Shepherd, Jacoby, Gabbay (2009)	England	Involvement in clinical governance.	Focus groups with citizens with a range of experience of NHS and involvement.
Litva, Coast, Donovan, Eyles, Shepherd, Tacchi, Abelson, Morgan (2002)	England	Involvement in healthcare decision making at three levels: system, programme and individual level.	Focus groups and interviews with a range of the public: experienced participants to novices.
Wiseman, Mooney, Berry, Tang (2003)	Australia	Involvement in priority setting across three levels: global, programme and between procedures.	Survey of patients in waiting rooms at two medical practices.

Three of the studies use focus groups and one employs a survey of patients, allowing all to reach a reasonably high number of respondents. Given the lack of pre-existing knowledge among some study participants, the manner in which the term is operationalised for these general studies is crucial. Litva et al specifically argue for a broad-based definition to make space for participants to specify their preferences:

“The term “involvement” was deliberately chosen because it is broad enough to encompass all rungs of Arnstein's ladder and would allow informants to discuss its meaning in relation to each particular decision making context. Similarly, the term “public” allowed informants to discuss who should be involved in these different contexts.” (Litva, et al., 2002, p. 1827)

Abelson et al's (2004) questions revolve instead around 'consultation', and experiences thereof, but remain broad and general. By contrast, the survey-based study was more specific about what involvement constitutes, and more limited in the scope of control available:

"respondents were asked whether the preferences of the general public should be used to inform each type of decision and whether the preferences of other groups (such as doctors, managers of health services, patients and their families, and so on) should be used to inform such decisions." (V. Wiseman, et al., 2003, p. 1008)

All four studies specified 'levels' of decision-making, from the macro (funding decisions) to the micro (whether certain patients should be given a particular treatment). However, it is unclear what was done to make the concept 'public involvement' meaningful. This is acknowledged as a concern: "The concepts of 'clinical governance' and 'public involvement' were not easily accessible to most lay informants. Thus focus groups were used to allow lay informants to discuss their perceptions about public involvement in three key aspects of clinical governance" (Litva, et al., 2009, p. 84). These articles go to considerable lengths to specify who the relevant 'public' are, and what the relevant decision is, but leave the nature of the 'involvement' under-specified.

The conclusions reached in these four studies (across three different countries) are remarkably consistent. They tend to advocate a shift away from the goals of "citizen control" (Arnstein, 1969) or "lay domination" (Feingold, 1977) advocated by authors in the 1960s and 1970s. Thus Litva, Canvin, Shepherd, Jacoby, and Gabbay conclude: "public involvement in any health-care initiative remains highly problematic until it is recognised that different users will take different role perspectives and desire different types of involvement in different aspects of the policy" (Litva, et al., 2009, p. 89). This is supported by Wiseman, Mooney, Berry, and Tang, who similarly reject the quest for citizen control:

"Citizens in this study felt that they have a legitimate role to play in priority setting in health care but that this role must be a joint one involving other groups, namely clinicians, health service managers, and patients and their families." (V. Wiseman, et al., 2003, p. 1010)

While Litva et al (2002) broadly concur, they introduce the useful notion of ‘accountable consultation’ as a goal; noting that citizens may be wary of having the final say, but do value feedback on how a decision has been made. In a later study, some of the same researchers promote ‘overseeing’ as an alternative to control (Litva, et al., 2009). Once again, though, questions of impact occur. Entwistle (2009, p. 2) points to the need for effective overseers to be seen as legitimate by organisational actors.

Overall, empirical studies of public involvement in health since the late 1990s have had a consistent and closely linked set of findings. They have repeatedly found problems and inadequacies in public involvement practice. These often manifest in the difficulties of balancing concerns around (demographic) representation with demands to demonstrate impact on structures and services. While a series of studies in the early 2000s attributed blame to NHS staff and managers for the failures of involvement, a number of more sympathetic studies pointed to the extent to which ideas around involvement challenge deep-rooted assumptions about (medical) knowledge and authority. Most recently, Learmonth, Martin and Warwick (2009) have pointed instead to public involvement policy creating problems by leaving too much unsaid, and creating ‘catch 22’ situations for staff and participants to work through. Consistently, though, this empirical research presents ‘the public’ as an unproblematic, even idealised entity. While several authors have called for us to re-evaluate the extent to which “citizen control” is a realistic or desirable goal for involvement, this is based upon the unwillingness of ‘the public’ to perform the necessary tasks to accomplish this. Staying firmly within a policy frame, more fundamental questions do not occur.

ASSESSING THE LITERATURE

This section moves from an overview of the existing literature to an assessment of the way it frames our knowledge of public involvement. In this I draw on Kuhn’s (1962) account of normal science, arguing that a specific set of approaches to this topic has to some extent become standard practice, limiting its analytic and critical potential. However, I also seek to demonstrate the ways in which this literature has evolved over the decades.

Since Arnstein's (1969) influential "ladder of participation", typologies of participation have become a common, even ubiquitous, feature of the public involvement literature. While some of this is a reaction against or in support of Arnstein (1969), typologies are more generally acknowledged to "be seductive in their capacity to simplify thought" (Weiss, 1994, p. 174). In the public involvement literature this tendency is closely linked to definitional struggles; abandoning the search for a catch-all description, numerous authors have turned instead to a system of classifications. In this reading, typologies have been one way to deal with the wide range of initiatives that profess to be 'involvement'. The epistemological status of these typologies is, though, unclear. A classic Weberian typology is a "pure conceptualisation ... to help us grasp our empirical cases by providing us with coherent models of what would exist if essential elements of the cases were in pure, idealized form" (Weiss, 1994, p. 176). These 'second order constructs' can be compared to the 'first order constructs' (Schutz, 1954) "constructed by participants in social systems" (McKinney, 1969, p. 2).

Typologies have structured analysis and discussion of public involvement over four decades. Although appearing merely descriptive, they grew out of a "paradigmatic phase" (Kuhn, 1962) which sought to critique specific instances of involvement. Initial papers in the 1960s and 70s came out of community activism and community development in the USA; they are highly normative, provocative, and action-oriented (Arnstein, 1969; Feingold, 1977). Thus Arnstein's (1969) influential typology aimed to uncover not merely tokenistic activities (a common goal in later studies) but even more malign manipulative and 'therapeutic' acts (the latter resonating with Edelman's (1974) critique of the 'helping professions'). Feingold's (1977) chapter, which sought to amend Arnstein's framework for health-specific contexts, argues that the community can join forces with administrators to oppose professional power. The 1980s were something of a quiet period for public involvement, as the literature was dominated by ideas of New Public Management.

It was in the late 1990s, in response to changing policy in the UK and as interest in governance became prevalent, that there was a resurgence in literature on public involvement. This literature is highly applied, and concerned primarily to improve practice within the frame of existing policy. It can be difficult to distinguish analyses 'of' policy, from analyses 'for' policy (Gordon, Lewis, & Young, 1997, p. 5). For example,

Healthy Democracy, a joint project between the NHS Centre for Patient and Public Involvement and Involve, simultaneously advocated New Labour's approach to involvement and explained how to 'do' involvement better (Andersson, et al., 2006). Many authors seek to assess progress against a pre-specified (if under-defined) goal of involvement, rendering much research evaluative rather than explanatory. Critiquing the "new pragmatism" in studies of health, Scambler and Britten argue that research funding has led to a disproportionate focus on "enhancing the effectiveness and efficiency" of interventions (Scambler & Britten, 2001, p. 47). Indeed, within this literature, significant continuities of approach and concern are evident, particularly in the six public involvement studies which were commissioned by the Department of Health in 1999 (Farrell, 2004). Members of these research teams contribute a disproportionate number of papers (W. Anderson & Florin, 2000; W. Anderson, et al., 2002; Coulter & Elwyn, 2002; Florin & Dixon, 2004; Lightfoot & Sloper, 2006; Milewa, 2004; Milewa, Dowswell, et al., 2002; Milewa, Harrison, et al., 2002; Thompson, 2003/2004; Tritter et al., 2003). Taken together, these articles can be seen as the foundations of knowledge on contemporary public involvement practice in the UK, and although many adopt a critical perspective, they are inevitably shaped by the concern to offer "evidence for policy implementation" (Farrell, 2004). Studies where practitioners report on – and defend – their experiences of public involvement (Murie & Douglas-Scott, 2004; O'Keefe & Hogg, 1999) also demonstrate a fairly uncritical attitude, with current policy taken as a starting point.

Following the resurgence in interest in public involvement during the New Labour era, it is also possible to discern a new perspective coming out of the first decade of the 21st century. At a remove from the case study approach of the 1990s, and in response to their narrative of failure, increased emphasis on public perspectives consistently indicates that different people seek different degrees of input, and that for many decisions, members of the public would prefer medical professionals to lead. This has led to a recent strain of literature arguing against Arnstein's (1969) approach (despite the fact that it had been present in name alone for some decades). Stepping away from the adversarial roots of public involvement, several articles advocated for involvement to be 'embedded' into health services, channelling the views of as wide a range of members of the public as possible, even at the risk of sacrificing the goal of 'citizen control' (Litva, et al., 2009; Tritter, 2009; Tritter & McCallum, 2006). This body of work argues that a goal of 'citizen control' will inevitably empower a small group of (most

likely already powerful) citizens at the expense of the majority. Accordingly, authors advocate a more flexible, integrated approach; in Tritter and McCallum’s language, a ‘mosaic’ instead of a ladder of involvement (Tritter & McCallum, 2006).

Table 1 sets out five typologies of public involvement from the literature which all concern themselves with defining the 'level' of involvement. Crucially, what is categorised within these typologies is an assessment of the degree of power gained by citizens, the public or specific service users. Thus, they offer not forms or practices of involvement, but summative evaluations of activities. While other authors have added the further dimension of ‘role’ (whether user or citizen) (Charles & Di Maio, 1993; Harrison, et al., 2002), level is the more consistent feature. Many, if not most, articles on the topic reference at least one of those featured in table 3.

Table 3: typologies of 'level' of involvement

Author	Arnstein	Feingold	Charles & Di Maio	Rowe & Frewer	Martin
Year	1969	1977	1992	2005	2009
Concept	‘citizen participation’	‘citizen participation’	‘lay participation’	‘public engagement’	‘public engagement’
Levels	manipulation				
	therapy				
	informing	informing		public communication	information
	consultation	consultation	consultation	public involvement	consultation
	placation				
	partnership	partnership	partnership	public participation	co-production
	delegated power	delegated power			
	citizen control	citizen control	lay domination		

Two points are worth making about table 3. Firstly, there is significant consistency in placement. Typologies can be easily mapped against each other, and even where the actual descriptor changes, the content of that ‘level’ (as defined in each article) is

reasonably consistent. Essentially, most are predicated on an increase in public power from top to bottom, with the exception of Rowe and Frewer (2005) who claim to construct their framework on the basis of information flows (from 'sponsor' to public, from public to 'sponsor', and between 'sponsor' and public). Involvement, engagement and participation sometimes appear as the umbrella concept, and sometimes as one level of an alternative concept. Regardless of terminological instability, the central concern is to determine how empowering any given instance of involvement is. My concern here is distinct from that of Tritter, who objects on the grounds that typologies:

"assume that all power is finite and that ceding power to one or other parties diminishes the power of the other rather than considering that there are different kinds of power and knowledge and that partnership and collaboration can bring about a better outcome." (Tritter, 2009, p. 276)

Instead, my objection is that, by building the basic categories of involvement on assessments of empowerment, these typologies have no awareness of practice, and assume that empowerment is a straightforward process on which we can all agree. Tritter's concern, essentially making a case for the shared interests of the public and professionals, only exacerbates the issue. Questions of power or assessments of 'better' outcomes, for me, need to be connected to some prior empirical content.

A further point revealed by table 3 is that, over time, typological levels have tended not just to reduce in number (as a straightforward simplification of Arnstein's (1969) typology) but to concentrate in the middle of the ladder. Both manipulation, and the aspirational inclusion of citizen control, fall away in more recent literature. In this way, these typologies have become less radical over time, with Arnstein's highly critical account diluted significantly. While one can hardly imagine local "engagers" (the staff tasked with doing participation) offering 'therapy' and 'manipulation' as their 'folk typifications' (McKinney, 1969) of their activities, the latter day alternatives of 'engagement' and 'involvement' are not necessarily drawn from meaningful distinctions of practice, but drawn *into* it. The concentration of typologies in an uncontroversial middle range of activities is likely connected to broader sociological shifts into what Scambler and Britten (2001, p. 46) call a "post-conflict" phase. In this period: "Some of those arguments *against* the medical profession, those unchallengeable criticisms of bureaucracy, those sure-fire positions of opposition against known enemies ... are no longer so easily bought" (G. Williams & Popay, 2001, p. 26). In periods where it is

unfashionable to emphasise conflicts of interest between medical services and their patients, and in research which is commissioned to improve policy and practice, the possibilities of conflict and domination within health care are downplayed. As the provocative content of early typologies has been excised, we are left with a framework that still fails to connect practice with outcome, but which now lacks the radical potential of its forebears.

A CONCEPTUAL ANALYSIS

Immersed in this literature, and wrestling with the number of “synonyms of uncertain equivalence” (Rowe & Frewer, 2005, p. 252), I became concerned about the most basic question: what *is* public involvement? In this section I will review how public involvement has been conceptualised in the existing literature. Stating the indeterminacy of the concept has become something of a lynchpin of introductory sections (Bishop & Davis, 2002; Bochel, Bochel, Somerville, & Worley, 2008; Conklin, Morris, & Nolte, 2010; Crawford, et al., 2002; Tritter, 2009). However, the literature has continued to grow apace. Very few studies raise fundamental question about the relevance of a distinctive concept of ‘public involvement’: where tensions are cited these are largely to be resolved at the level of practice, not theory. In this section I apply Sartori’s (1970) critique of concept misformation to existing accounts of public involvement, arguing that ‘public involvement’ offers not a “fact-finding and fact-storing container” (Sartori, 1970, p. 1043) but rather an empty signifier around which observations accumulate. While this is but one understanding of the nature and function of concepts (Adcock, 2005), it seems an appropriate choice given the very practical concerns of these authors.

The literature revolves around a range of compounds formed by adding a named group of participants (‘public’ ‘patient’ ‘citizen’ and ‘user’) to a type of activity (‘involvement’ ‘engagement’ and ‘participation’). The result is literature that shares a family resemblance (Wittgenstein, 1953) rather than a terminological grounding. One recent editorial for a ‘virtual special issue’ on public participation in health describes searching the archives of the journal *Social Science and Medicine*: “each of the search terms ‘public’ and ‘community’ was combined with each of the terms ‘participation, engagement, deliberation and involvement” (Tenbensel, 2010, p. 1). By and large this curious

instability – resulting in what Rowe and Frewer (2005, p. 252) describe as “synonyms of uncertain equivalence” – is given little attention within the literature. As one paper puts it, with little explanation, “involvement will be considered as a generic term that encompasses the notions of participation, consultation and engagement” (Wait & Nolte, 2006, p. 152). Other papers choose an alternative umbrella concept and consider involvement as a subset (Rowe & Frewer, 2005). Perhaps the most common response to this discursive instability is to shift repeatedly and without explanation between different terms. As an illustrative example, O’Keefe and Hogg (1999) use ‘public participation’ in their title, select ‘user involvement’ as a keyword, ‘public involvement’ in their abstract, and in the body of the article shift apparently arbitrarily between ‘community involvement’, ‘user involvement’, ‘public involvement’, ‘user participation’, and ‘community participation’ (with the titular term ‘public participation’ neither defined nor used thereafter). Occasional exceptions to this include the ascription of certain characteristics to particular words, such as Bochel et al.’s statement “the terms consultation and participation suggest different degrees of involvement” (Bochel, et al., 2008, p. 202). It is unclear whether these are reportive definitions, relying on perceived common usage, or stipulative definitions, offered for future analyses. Occasionally trends emerge whereby certain terms become particularly common in specific contexts or periods. For example, ‘patient and public involvement’ as an analytic category seems to be a predominantly UK-based construction associated with New Labour policy of the late 1990s and 2000s (Forster & Gabe, 2008).

I argue that this terminological instability is not merely semantic but denotes disagreement about the ontology and purposes of public involvement; the basic phenomenon of interest is disputed. Regarding the basic question of what ‘counts’ (and crucially, does not ‘count’) as involvement, at least two distinct understandings are present within the literature. Firstly, several papers focus on public involvement as a governmental or organisational action (albeit one which creates opportunities for public action). Many papers explicitly or implicitly identify public involvement as something to be found in policy documents; an exhortation to staff: “a succession of policy initiatives designed to make the NHS more aware of patient views, more sensitive to consumers and more accountable to the public” (Klein, 2004, p. 207). Alternatively, Andersson, Tritter and Wilson introduce it as something akin to an ethos, or perhaps a toolkit of approaches: “a number of ways of working that all share a commitment to involving the public” (Andersson, et al., 2006, p. 9). By contrast, other authors discuss public

involvement as a naturally occurring, out-there phenomenon, foregrounding not organisational initiative but rather public action. This leads to definitions such as “ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organisation and delivery of health services” (Tritter, 2009, p. 276), and “the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients” (Crawford, et al., 2002, p. 1).

Other papers simply employ both understandings: Anton, McKee, Harrison, and Farrar (2007) introduce public involvement as governmental action and then include bottom-up action as the analysis proceeds. They start with the definition: “Attempts on the parts of organisations such as Health Boards to include a range of (often unspecified) individuals and groups ... and the ‘public at large’ in their activities” (Anton, et al., 2007, p. 470). However, within a few paragraphs it becomes clear that public involvement is not merely understood as these events: the Board: “officially initiated a number of Public involvement activities. However, latterly, public involvement took place as part of a reaction against the emerging outcomes of these events” (Anton, et al., 2007, p. 473). It is unclear whether the capitalisation here distinguishes official activities from unofficial, but there are evidently two understandings of involvement present within the article.

While one could argue that this is not contradictory, it does stretch the concept. The key issue here is one of initiation: if a (disgruntled) public response to the decisions reached by an organisation’s involvement activities also constitutes public involvement, we reach an unsatisfactory situation where any public action directed towards the NHS ‘counts’ as public involvement. Sartori identified this risk within studies of ‘participation’ and ‘mobilisation’ as long ago as 1970:

“Participation means self-motion ... so conceived, participation is the very opposite, or the very reverse, of mobilisation. Mobilisation does not convey the idea of individual self-motion, but the idea of a malleable, passive collectivity which is being put into motion at the whim of persuasive – and more than persuasive – authorities.
..[P]articipation is currently applied by the discipline at large both to democratic and mobilisational techniques of political activation.” (Sartori, 1970, pp. 1050-1051)

I argue that public involvement is a tricky phenomenon, in which both state-initiation and citizen participation are integral. A quote which captures this simply and effectively is Barnes' definition of citizen participation more broadly as "a dialogue between private lives and public policy" (M. Barnes, 2004b). In approaching the topic from two different starting points (placing either one or the other actor as sole agent), more analytic depth is sacrificed than is warranted.

As highlighted above, a further dimension of rarely articulated disagreement within this literature relates to the goals and purposes of public involvement. In an editorial on the topic, Harrison, Dowsell, and Milewa (2002) depict three 'literatures' of public involvement: consumerist, democratic and 'New Social Movement'. In their characterisation, the consumerist literature is concerned with "the exercise of 'effective demand' (that is, desire backed by money) in a market"; the democratic is simply that concerning democracy (whether representative/liberal or direct/participatory); and the New Social Movement literature concerns "pressure groups, networks and New Social Movements ... which are concerned with proactive social action" (Harrison, et al., 2002, pp. 63-64). I find this tripartite distinction illuminating, although it requires some reformulation for my purposes. Firstly, I simply feel that there is scope for a bolder statement. Authors have indeed approached this topic from stances which tend to create distinct literatures, but I argue that this pervades our ideas and practice as well as analysis, and therefore goes beyond a classification of literature. These three groupings reflect deeper divisions in approach. The concerns of (consumeristic) public management scholars are often rooted in organisational effectiveness, which is assumed to be a broadly straightforward goal. Although he is cited enthusiastically across the literature, this is the natural home for Hirschman's (1970) work. As one health economist politely pointed out to me at a conference, as long as *someone* is 'voicing' concerns about an organisation, it is not of great concern whether young people are. Researchers working from the perspective of New Social Movements, or, to a lesser extent, democracy and political participation, would likely dispute this. For these researchers, the lessons of the disability movement and other user groups are that mainstream preferences for an organisation can be profoundly at odds with what some of the most vulnerable sections of the population need. Barnes, for example, consistently asserts the value and legitimacy of organised user groups in participatory initiatives, because they have distinctive expertise on services (M. Barnes, 1999, 2007). For scholars concerned with an overarching picture of democracy and participation, rather

than the particular needs of vulnerable groups, concerns are about “the fundamental democratic tests of popular control and political equality” (Lowndes, Pratchett, & Stoker, 2001, p. 215). To describe these merely as different literatures underplays their more deep-rooted differences.

Secondly, all three of the groupings are somewhat vague – as befits the stated aim of the editorial as a “preliminary sketch” (Harrison, et al., 2002, p. 65). In particular, the inclusion of mechanisms of patient choice in the consumerist approach is unusual, given that this is often seen as an *alternative* mechanism to voice-based public involvement (Greener, 2008). Including market mechanisms means the authors neglect the other ways that consumerism is said to seep into voice mechanisms (Newman & Vidler, 2006), such as Lowndes, Pratchett, and Stoker’s (2001) description of complaints schemes, satisfaction surveys and opinion polls as consumerist methods of participation. The distinction between a democratic literature and a New Social Movement literature is, for me, one of the most valuable aspects of Harrison, Dowsell and Milewa’s framework, but again the explanation emphasises the topics of the literatures (“unlike the citizenship literature, the focus [of New Social Movement literature] tends to be both empirical and upon some form of collective action” (Harrison, et al., 2002, p. 64)) rather than authors’ concerns or approaches. To clarify this distinction as one more profound than the presence or absence of empirical content, I re-frame the New Social Movement category as ‘emancipatory’. This reflects a particular concern with marginalised groups, in that authors and projects are concerned:

“To discriminate in favour of particular groups or areas, especially where authorities are trying to reach socially excluded groups. In this respect, they automatically fail the democratic test, even though they may be seeking to address failings in existing democratic practice.” (Lowndes, et al., 2001, p. 215)

Thus, I draw on Harrison, Dowsell, and Milewa’s (2002) initial argument to depict not three literatures, but three sets of concerns or purposes within public involvement and its literature: the democratic, the consumerist, and the emancipatory.

Disagreement about the ontology and purposes of public involvement within (as well as between) individual studies is not unexpected. However, it creates problems which are reproduced as subsequent studies build on the same references. It has enabled a

significant body of literature to build up without a coherent purpose, and allowed debates to emerge on uncertain, shifting ground. Although other authors have asked profound questions about the nature of public involvement, this is generally in the form of a very normative discussion on whether participation is understood as a means to some other end, or an end in itself. Martin's (2008b) discussion of 'democratic' versus 'technocratic' rationales for public involvement – like Charles and Di Maio's (1993) discussion of participation as an end in itself or as a means to an end – is concerned with 'good' and 'bad' examples of public involvement and not with demarcating the nature of the phenomenon. Bochel et al review some of the assumed benefits of involvement: "participation might be intended to improve governance, democracy, social capital, education and development of individuals, policies, service implementation and delivery – all, or one or more of these, or something else altogether" (Bochel, et al., 2008, p. 202). While highlighting this remarkable range of possible purposes, the authors nonetheless conclude by re-stating their commitment to the possibility of "successful" or "real" participation (Bochel, et al., 2008). The under-specification of public involvement constitutes an example of conceptual stretching, in that we are not "able to distinguish A from whatever is not-A" (Sartori, 1984, p. 74).

One way to understand the reasons for this imprecision is – at the risk of irritating those who argue the term has meaning only within the context of a semiotic analysis (Jeffares, 2008) – to consider public involvement as an empty signifier. Drawing from the discourse theory of Laclau (1996, 2005), empty signifiers begin within a range of descriptors/signifiers used to refer to some phenomenon (the signified). As the 'chain' of descriptors grows, one becomes dominant, and with use it loses its attachment to the particular meanings it once held (it is emptied of this meaning). Thus, the signifier comes to encompass all the potential 'claims' about the signified phenomenon but also crucially encompasses an "unachievable fullness" (Laclau, 2005, p. 71). In the case of public involvement, I argue that we can discern a range of competing claims/demands associated with the broad topic of empowering members of the public within health services. Over time, as this 'chain' of claims grows and becomes untenably long, 'public involvement' becomes the dominant signifier in the UK context. As it now stands for a broad range of phenomena, with some degree of family resemblance (but, I would argue, far less than is conventionally assumed), the term is emptied of its original meanings. It does, however, retain an appeal as a symbol of perfectibility; it refers not merely to a process or some stage along the way, but to the end goal. In this case, 'public

involvement' contains an eternal fantasy of an ideal state, yet offers few handholds for actors trying to work towards it. Bastow and Martin's analysis of 'community' as empty signifier describes this as "symbolisation of a presence yet to come" (Bastow & Martin, 2003, p. 42).

I would argue that the under-specification of public involvement – the extent to which the referent has become decoupled from the referred – is functional in that it allows policy-makers, practitioners and analysts to go about their business without having to resolve the uncertainties and conflicts contained within the phenomenon. As Katherine Smith outlines, 'chameleonic' ideas "may be presented in quite critical ways to academic audiences but imbued with a vagueness facilitating their transformation into less radical versions of themselves within policy" (K. E. Smith, 2010, p. 189). This perspective also opens up consideration of how one signifier gains dominance over others (for example 'citizen engagement' or 'public participation'). Griggs and Howarth (2002) argue that empty signifiers become dominant by a combination of availability, 'credibility' and support from key agents. I would argue that in the UK context, use of 'public involvement' by the Department of Health was critical in the dominance of this terminology over alternatives. This included the creation of an 'evidence library' and funding streams for research (Farrell, 2004), as well as explicit use in the naming of key initiatives (the Commission for Patient and Public Involvement in Health). Academic researchers are drawn into this via research funding, and via researching specific policy initiatives which employ the terminology. Perhaps an extreme example is Tritter's advocacy of the terminology of patient and public involvement (Tritter, 2009), published while he held a grant from the Department of Health to contribute to the evidence-base for patient and public involvement, while occupying the position of Research Professor of Patient and Public Involvement in the NHS Centre for Involvement at Warwick University³.

³ Identifying key agents of a signifier's ascent also enables us to consider what happens when that support is withdrawn, as in the case of the end of NHS funding for the Warwick Research Centre, and the 2010 integration of the online NHS Evidence Library on patient and public involvement into one on commissioning..

This section has pointed to the extent to which the literature I assemble and identify as 'public involvement in health' is built on unstable terrain. Behind a loosely connected set of referents, I would argue that there is little shared conceptual foundation. This 'faulty connection' between the realms of academic discussion and the activity it seeks to analyse has allowed significant changes in policy and practice to be poorly chronicled. Academic discussion has twisted and flexed – to the mutual benefit of both analysts and policy-makers – to present apparent conceptual consistency in a field of transformation. As several others have argued, it may be time to stop the stream of refined typologies and instead attempt to produce fuller understandings of the practice and consequences of public involvement. For Contandriopoulos (2004, p. 328) "public participation is only that indistinct and undefined part of normal political and administrative behaviours we are used to calling that way". Less radically, for Conklin, Morris, and Nolte (2010, p. 9) it is simply "a descriptive umbrella term for the spectrum of processes and activities that bring the public into the decision-making process". Despite the frustrations of working within a literature which exists on such shifting sands, this thesis aims not to be "too purist in our search for theoretical rigour and coherence" (Greenhalgh, et al., 2005, p. 418). Adcock similarly cautions against the search for univocality when working with concepts, and instead advises reflexivity about "what it is that we seek to do (and what we are not seeking to do) when we engage in a particular 'concept' focused discussion" (Adcock, 2005, p. 32). Instead, this thesis aims to uncover and explicate the multiple strands of intention and practice contained within the phenomenon of public involvement in health.

A WIDER FRAME: SOCIAL SCIENTIFIC ANALYSES

The previous sections have characterised four decades of literature on public involvement in health which, I would argue, have yielded useful observations while lacking the conceptual framework to progress up Sartori's 'ladder of abstraction': "the vagueness of the theory has no fit for the specificity of the findings. We are thus left with a body of literature that gives the frustrating feeling of dismantling theoretically whatever it discovers empirically" (Sartori, 1970, p. 1043). As discussed above, recognition of the unsatisfactory state of theoretical accounts of public involvement has prompted several authors to turn away from conceptual development (Conklin, et al., 2010; Contandriopoulos, 2004). I agree that public involvement can be usefully understood as a realm of action, and also that attempts to "conceptualise" it have been

unsuccessful (Tritter, 2009). Instead of persevering in attempts to build a conceptual model within the interdisciplinary context of health services research, I suggest we try instead to locate different understandings of public involvement within broader social scientific accounts of participation and governance. Reusing the distinction between governmental and public action identified above, in this section I will firstly locate public involvement in health within broader academic accounts of civic and political participation. This essentially speaks to the literature which examines public involvement as public action. Secondly, I will explore literature which considers engagement techniques as mobilisational technologies of government; where a clear link can be discerned with literature which examines public involvement primarily as governmental initiative.

The literature discussed in this section is an eclectic, although not arbitrary, selection of studies which offer illuminating perspectives on the topic of public involvement in health. Most – for example studies of participation in other public services and local government – are obvious complements to a review of public involvement in health services. (In the interests of brevity, I do not attempt to review the whole of this literature, but instead highlight studies which I feel offer genuinely novel perspectives, demonstrating different approaches from those which I have identified within the health services literature.) However several of my choices step deliberately away from the historical or geographical frame in which public involvement literature is situated. In the same way that attending to the full length of Arnstein's (1969) ladder helps us to recognize how conservative contemporary typologies have become, these texts help us to recognize the enduring appeal of participatory policies, and the particularities of governmental projects in particular place and time. Cruikshank analyses community-level technologies of government in the USA in the late 1980s, arguing for recognition of "the political effects of the will to empower" (Cruikshank, 1999, p. 124). Sharma draws on Cruikshank's analysis in her ethnographic account of a women's project in rural India in the late 1990s, analysing empowerment as "an emancipation tactic that doubles as a technology of government and development" (Sharma, 2008, p. 29). I hope that this section demonstrates the value of these studies in helping me to find a standpoint outwith the existing literature, and to understand the topic of public involvement as part of broader trends in participation and governance.

PUBLIC INVOLVEMENT AS PARTICIPATION

Instead of seeing public involvement as a unique phenomenon (or even concept), this section seeks to demonstrate connections between involvement and the literatures of political participation and more general civic engagement. For citizens 'doing' public involvement in the public services, it occupies an odd hinterland between political participation and privatised action. It is in good company, along with a range of activities formerly understood by political scientists as predominantly private, but increasingly seen as at least potentially political. Schumpeterian traditions of the study of political participation focus simply on voting in elections for legislatures (Schumpeter, 1943). Classic empirical studies (Burns, Schlozman, & Verba, 2001; G. Parry, Moyser, & Day, 1992; Verba, Nie, & Kim, 1987) include all activity explicitly aimed at the government so that participation aims to influence the decisions made by, as well as the personnel within, government (Teorell, 2006). Definitions have expanded further partly as the boundaries of what we recognise as 'the political' have stretched (Stoker, 2006). Analyses have moved beyond activities aimed at the institutions of representative democracy, so that consumer decisions such as boycotting large multinational companies (Stolle, Hooghe, & Micheletti, 2005) or donating money to a nongovernmental organisation (Harris, Wyn, & Younes, 2010) are recognised as everyday forms of political participation. Feminist critiques point to oppression and resistance occurring as much in spaces traditionally understood as private as in those we have thought of as public (K. B. Jones & Jónasdóttir, 1988).

Given this expanded understanding of political participation, public involvement (with its focus on state-provided services) seems more obviously political than many other newly-deemed political acts. However Warren (1996, p. 246) argues that the focus on state-targeted action misses the point, stating that "Much of what we consider to be within the realm of the state may be virtually uncontested...and so may be much less political than institutions outside of the state engaging in contested practices".

Questioning the extent to which public involvement is a practice of contestation offers another interesting perspective. As a participatory activity, public involvement can also be seen through the lens of social activities such as volunteering. Harre (2007) distinguishes activism and voluntarism on the grounds that activism seeks to change structures, while voluntarism seeks to directly meet perceived needs. These literatures remain curiously distinct despite their common ground in citizens taking action within

their community or wider society: Super (2009, p. 9) argues that the distance between analyses of 'civic engagement' and of 'political action' is not a gap in the literature but "a gap *between* different fields of research". Thus there is no shortage of literature on voluntarism or on political action, but analysts conventionally ask very different questions of them, particularly as regards motivation for and benefits of taking part. Specifically, scholars of voluntarism rarely question whether activity contributes to changing structures. Rather as a form of 'public service' volunteering is more often seen as concerned with meeting unmet need in a direct fashion. By contrast, political participation is generally associated with change- or influence-seeking.

The key concerns of academic literature on political participation have been with the quantification of participation – who participates and how much – and with a perceived decline in quantity over time. *Democracy at risk*, a 2005 publication which brought together high profile American scholars under the auspices of the American Political Science Association, was premised upon the common statement that "all is not well in our civic life. Citizens are participating in public affairs too infrequently, too unequally, and in too few venues" (Macedo, 2005, p. 1). Alternative accounts have drawn more optimistic conclusions, with work by Norris (2002), Dalton (2008) and Pattie, Seyd and Whiteley (2004) asserting a change – rather than a decline – in engagement. Attempts to explain patterns of participation have preoccupied political science for decades. Burns, Schlozman and Verba (2001) characterize a progression within their own scholarship through three stages of analyses of participation: Verba, Nie and Kim's (1987) 'SES model', which links levels of participation to socio-economic status, primarily through income and level of education; Verba, Schlozman and Brady's (1995) 'civic voluntarism model', which seeks to explain on the basis of resources, generalized political engagement and recruitment, and finally approaches which seek to understand 'the private roots of public action'. All of these are based on sophisticated quantitative analysis of survey data. A number of dissenting voices dispute the normative focus on increasing participation. Hibbing and Theiss-More's *Stealth Democracy* works with survey data to argue against stronger versions of democracy: "most citizens do not care about most policies and therefore are content to turn over decision-making authority to someone else" (Hibbing & Theiss-Morse, 2002, p. i). Alternatively, others identify the unattractive characteristics of political action. Warren points to the 'essential groundlessness' of political action, "radical democrats would do well to recognise the inherent discomforts of politics...If [people don't participate] it may not be just because

our culture induces apathy and excessive individualism but also because of unattractive features of politics as such” (Warren, 1996, p. 266).

As the context of political participation has altered, some scholars have sought to understand the nature of new opportunities and modes of participation. Bang (2005; Bang & Sorensen, 1999) argues that contemporary governance has created space for two new types of participant: the ‘expert citizen’ and the ‘everyday maker’. Expert citizens operate within increasingly formalised, even professionalised invited spaces for participation: “What is of concern to them is no longer fighting the system as a ‘constitutive other’ but rather gaining access to the bargaining processes which go on between public authorities and various experts” (Bang, 2005, p. 165). By contrast ‘everyday makers’ make up what conventional political science would consider the apathetic majority. “They consider knowing as doing, refusing to take on a professional, full-time or strategic citizen identity. They want to do things in their own way, right where they are, when they have time or when they feel like it. Their engagement is more ‘on and off’ and ‘hit and run’ than that of the expert activist” (Bang, 2005, p. 162). While the idea of the expert citizen resonates with accounts of the ‘usual suspects’ in public involvement initiatives – fleshing out the demographic definition to incorporate notions of expertise and praxis – it is the notion of the everyday maker that is genuinely novel. Bang’s case study of local politics in an area of Copenhagen identifies young people as particularly prevalent everyday makers, and the emphasis on doing not influencing, and short intense bursts of participatory activity is instructive when considering how individuals choose to participate in the NHS. A more prosaic account of the range of types of participation available within new participatory spaces is offered by Simmons and Birchall’s (2005) useful typology. While they concentrate mostly on elaborating their ‘mutual incentives’ theory of motivation to participate, they also recognise five types of participant (campaigners, foot soldiers, scrutineers, habitual participants, and marginal participants) (Simmons & Birchall, 2005, pp. 269-270).

PUBLIC INVOLVEMENT AS GOVERNMENTAL ACTION

Health services research on public involvement tends to start the ‘story’ with the intervention of organisations such as the World Health Organisation, who placed participation near the top of their agenda for health services in the 21st century (World

Health Organisation, 1998). However the rise of public involvement can also be seen in the context of the broader history of citizen participation and empowerment as governmental projects. These analyses attempt to understand broader trends which have brought citizen participation to the forefront of policy, moving up the 'ladder of abstraction' from considerations of the role played by the World Health Organisation or Department of Health. Sharma (2008, p. xviii) sees empowerment projects emerging within development policy as the consequence of an unlikely intersection between grassroots activism, informed by Freire's pedagogy, and the IMF-driven liberalization of the Indian economy. While this resembles conventional explanations for public involvement in the NHS (top-down drive for accountability plus bottom-up action of social movements) Sharma weaves recognition of this tension through her analysis. For her, the "awkward confluences" between different uses of empowerment should be at the heart of any analysis: "Empowerment as a quasi-state-implemented governmental strategy is a double-edged sword that is both promising and precarious" (Sharma, 2008, p. 198).

Other authors direct our attention primarily to the top-down rationales for empowerment initiatives. Cruikshank analyses involvement strategies in American Community Action Programmes (CAPs), and in particular the shift from a focus on objective causes of poverty (low wages, racism, and unemployment) to its subjective dimensions:

"The subjective causes of powerlessness became the object of intense governmentalisation in these programs, primarily because the poor often chose not to participate and failed to constitute themselves as a constituency for antipoverty policy. Their 'apathy' and political inaction became the central target of programs." (Cruikshank, 1999, p. 73)

Warren remarks on the administrative, rather than political, origins of many citizen participation initiatives:

"Policy and administration are moving into the front lines of the project of democratisation. On the face of it, this development comes as something of a surprise to those who have viewed democratisation as the mission of class agents and social movements, or as a matter of establishing and reforming electoral processes and the rule of law." (Warren, 2009b, p. 3)

New avenues of citizen participation are thus a response to the broader democratic deficit and the increased complexity of governing; but they are understood as a human response, which comes from the lived experience of administrators and policy-makers: “policy –makers are on the front lines of this new pluralized ungovernability ...generating legitimacy ‘locally’ – issue by issue, policy by policy, and constituency by constituency” (Warren, 2009b, p. 8). Bang (2004) similarly argues that the move towards what he terms ‘culture governance’ – collaborative and communicative modes of governing – is as much about survival of systems of authority in the face of a reduction of control as it is belief in the need for change. Taking as their topic participation as a policy of the New Labour government in the UK, Barnes, Newman, and Sullivan (2007) bring together analyses of a range of participatory projects and discuss them as part of a broader trend. They identify four governmental objectives which participation was presented as furthering: improved public services, improved population outcomes, and democratic renewal at both institutional and individual/community level (M. Barnes, et al., 2007).

All of these authors argue for a political, as opposed to technical or administrative, analysis of participatory initiatives: “empowerment is a risky and deeply political act whose results cannot be known in advance” (Sharma, 2008, p. xx). Barnes, Newman, and Sullivan conclude by arguing that the emphasis on techniques of participation has distracted from central questions about whether publics are enabled (and able) “to challenge dominant rules and norms and to question the ways in which the rules of the game are defined” (M. Barnes, et al., 2007, p. 201). Warren (2009a, p. 18) argues that “the administrative contexts have perhaps masked the essentially political nature of these developments. We have not really grappled systematically with the question as to what more ‘citizen engagement’ in this sense would mean for the democratic system as whole.” Thus the consequences of participatory initiatives are understood as having implications beyond the specific decision or organisation they exist within.

This influences the extent to which we can demarcate 'good' and 'bad' participatory initiatives, a focus strongly associated with technical accounts. Warren’s (2009a, 2009b) concerns are not radical, and are firmly grounded in consideration of the consequences of “the degree to which politics – and democratic demand – has flowed into venues outside of electoral representation” (Warren, 2009a, p. 16). Stating that we already have

robust empirical observations of 'what works' in participation (what I term technical accounts), Warren argues that we need to develop a middle level theory which explores the broader democratic consequences of such initiatives. Barnes, Newman, and Sullivan (2007, pp. 36-37) argue that Habermasian idealism pervades much research on participation. However they remain committed to the principles of participation, arguing that even imperfect participatory institutions are better than what came before. By contrast, Sharma (2008) and Cruikshank (1999) are concerned primarily with the discursive existence of empowerment. Sharma rejects attempts to characterise an essential core of what empowerment is, in favour of an attempt to "interrogate what these ideas mean in practice and how they are brought to life through everyday actions and interactions" (Sharma, 2008, p. xix).

Both Cruikshank and Sharma would object to general assessments of the potential of participatory initiatives, preferring instead to caution against naivety and call for attention to specific instances. Cruikshank's Foucauldian analysis traces the career of 'empowerment' from social movements and radical activists in the 1960s to its neoconservative manifestations in the 1980s. She argues that the tactics of empowerment programs are consistent in each: "to act upon others by getting them to act in their own interest. It is the content of powerless people's interests over which the right and the left disagree" (Cruikshank, 1999, p. 68). So in the case of CAPs, she argues against the dominant leftist critique that the War on Poverty 'co-opted and repressed' the poor. Instead she argues that it first 'invented' the poor as a distinct constituency and then went on to generate space within this constituency for political opposition: "the implicit elitism of the will to empower, claiming to know what is best for others, does not condemn it to failure or necessarily to a reactionary status" (Cruikshank, 1999, p. 86). Sharma similarly takes issue with the international development critique of the bureaucratisation and professionalisation of participation (Cooke & Kothari, 2001; Ferguson, 1994). She argues, essentially, for recognition of the residual 'genie out of the bottle' potential of empowerment:

"Governmental programs do not simply fashion bureaucratized and passive state subjects. In postcolonial contexts these programs are generative in that they produce active, sometimes dissident political actors...Governmentalisation does not depoliticise so much as it spawns openings for a subaltern politics of citizenship that may take new, unexpected forms." (Sharma, 2008, p. 196)

CONCLUSION

Public involvement in health has yielded a substantial literature. In this chapter I have argued that discussion of public involvement in health has been ghettoised into health services research and away from broader social science analyses of public roles in governance. I highlight some of the insights which empirical studies have yielded; painting a picture of managerial and professional manipulation, tokenistic initiatives and public ambivalence to opportunities for involvement. Analysing the literature, I seek to demonstrate that analyses have become preoccupied with offering technical advice on the implementation of policy rather than understanding phenomena for their own sake. As a result, problematic trends have arisen within the literature. Firstly, the presence within the topic of two key actors (state and public) and multiple potential rationales (the consumerist, the democratic and the emancipatory) has created disagreement whereby terminology has become detached from the phenomena it describes. The literature has solidified around an under-specified concept ('public involvement') which offers a functional instability for authors. Secondly, while key articles such as Arnstein's (1969) radical, provocative 'ladder of participation' continue to be widely cited, the literature has become decoupled from the author's stance and understandings of involvement have become reduced down to cohere with definitions from policy.

I identify chronological eras of public involvement research, and argue for a more explicit recognition of the dramatic makeover of the core concept. In response to these difficulties, there is a growing trend to understand public involvement as a descriptive topic, not a distinctive concept. Having reflected on some of the tensions within this literature, I consider links with the broader social science literature on participation and governance, seeking to justify a wider frame which understands public involvement policy and practice in the context of societal shifts towards governance. The usefulness of these perspectives will be demonstrated as the thesis progresses. For now, these studies can be understood as offering an alternative vantage point from which to survey existing knowledge on the topic of public involvement in health.

3. DESIGN AND METHODS

Field research is an unpredictable process. Genuine engagement with the world outside should challenge the research designs that we draft at our desks. Firebaugh (2008) lists the possibility of surprise as his first rule of social research: Charmaz urges researchers to embrace “the existential dislocation of bewilderment” (Charmaz, 2004, p. 991).

Fieldwork for this project was surprising, in that it made me recognise my assumptions about the policy and practice that I studied, and amend my research design accordingly. The project started out as an investigation of young adults’ experience and perceptions of the NHS, with a scene-setting exploration of the opportunities for young adults to influence local services. I assumed that public involvement – a policy agenda familiar from Government documents and local strategies – was a reasonably self-evident phenomenon, and I sought simply to know its local implementation in order to inform interviews with young adults. What emerged was a project centrally concerned with puzzles around the nature of this ‘self-evident’ phenomenon, in which interviews with young adults were an invaluable lens through which to view the phenomenon of interest, and not themselves the central topic. I describe my research design as an interpretive case study of public involvement in one locale, in which I used semi-structured interviews, observation, and documentary analysis to develop a picture of the richness and complexity therein. This chapter is structured chronologically, seeking to tell the story of this project in order to enable the reader to assess the quality of the research. I begin by introducing the project I had drafted before entering the field, including a discussion of the interview pilots which first prompted me to rethink my approach. I then reflect on the process of data collection as it developed in the field and discuss data analysis and writing as processes of sense-making, culminating in this thesis as written record.

PLANNING

THE INTELLECTUAL PUZZLE AND INITIAL RESEARCH DESIGN

My interest in this topic arose while working in the voluntary sector in England for a national organisation which sought to support its local activists to ‘get involved’ with public involvement. I therefore started from very practical concerns about policies of

public involvement, but also from the perspective of the public. I am not, however, on an impassioned crusade about patients in the NHS (see for example Coulter, 2002). Indeed, I feel that the example of newly empowered citizens in the NHS challenges simple dichotomies between ‘underdog’ and ‘overdog’ research (Becker, 1967), reflecting more nuanced post-structural conceptions of power (M. Foucault, 1984). Given the current knowledge on public involvement discussed in chapter 2, I developed a research design to explore two of the “intellectual puzzles” (Mason, 2002) therein. Firstly, I wanted to work through the ontology of public involvement, moving beyond the conventional typologies – involvement, engagement, control – which have grown out of Arnstein’s (1969) original contribution. I sought a clearer understanding of the day-to-day activities and practice of public involvement in the Scottish NHS. This puzzle necessitates exploration of the institutional context of public involvement activity. Secondly, frustrated by the generalised, idealised ‘public’ which dominates the discourse of involvement, I wanted to consider dilemmas around ‘who’ is involved. This second puzzle entailed a different approach, exploring not just how involvement is practised but the absences it creates or permits.

As the project progressed, these two puzzles sometimes seemed incompatible foci for the research. Weiss sees these two approaches – a concern with the institutions of an issue and with the population it affects – as inter-related but distinct: “We would then be doing two distinct studies. They would enrich each other, but our workload would be greater” (Weiss, 1994, p. 18). By contrast, I see these two approaches as contributing to a single study. The full rationale for this conviction emerged only during fieldwork, and is accordingly discussed further in the penultimate section of this chapter. Essentially the puzzles in my research boil down to ‘who is the public?’ and ‘what is involvement?’ This was operationalised in the following research questions.

1. How is public involvement operating at the local level in Scotland?
2. How are young adults using the public involvement mechanisms available to them?
3. What are the reasons for limited or non-use of public involvement mechanisms by young adults?
4. What are the implications of limited or non-use of public involvement mechanisms by young adults?

My approach is strongly shaped by a commitment to studying localised experiences and perceptions. Much of the literature on public involvement moves quickly from empirical findings to abstract typologies and recommendations for improvement; “the normative slides uneasily into the descriptive” (Mahony, Newman, & Barnett, 2010, p. 1). The very grammar of public involvement is significant. Dorothy E. Smith critiques academic literature’s commitment to nominalisation (whereby verbs are transposed into nouns): “thus eliminating the textual presence of what is done by people” (D. E. Smith, 2001, p. 166). A commitment to understanding public involvement as ‘done’ by local actors entails that my research strategy most closely resembles Blaikie’s ‘abductive’ logic of enquiry.

“At one level, the accounts of a social world produced by the social scientist are redescrptions in social scientific language of the social actors’ everyday accounts. At another level, these redescrptions can be developed into theories that go beyond everyday knowledge to include conditions of which social actors may be unaware.” (Blaikie, 2000, p. 116)

This strategy both stems from and commits me to an interpretive constructivist paradigm comprising “a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of methodological procedures” (Denzin & Lincoln, 2003, p. 35).

Interpretive research is a broad church: “There are far fewer fixed regulations in the discourse of interpretive scholarship than there are in more conventional forms of inquiry” (Lincoln, 2002, p. 327). One prominent edited collection summarises the ontological and epistemological preoccupations of the interpretive turn thus: “the inevitable role played by researchers’ a priori knowledge, their and their research subjects’ situatedness in a context, and the interactions and entanglements between consciousness and the action, artefact, and textual embodiments of meaning” (Schwartz-Shea & Yanow, 2006, p. 3). It seems to me that these are not uniquely interpretive themes, and yet I consistently find the work of scholars who subscribe to an interpretive approach illuminating and convincing. One admirably clear statement of why one author uses the term interpretive is that offered by Soss (2006, p. 132) in his “practice-centred view of interviewing for interpretive research”. Following this, I prioritise scepticism

about shared meaning, foreground my interviewees' own sense-making ("the logics that made a host of obscure, seemingly unrelated narratives explicable"), and seek to understand their behaviour as reasonable. In this project I have been sceptical about the idea that 'public involvement' means the same thing to the range of actors I have encountered in the field, have endeavoured to place their understandings and explanations of their activity centre-stage, and have searched for 'coherence' between action (turning up, sitting through meetings) and understandings (of appropriate behaviour, of the right thing to do).

Interpretive studies are both increasingly common and increasingly accepted as a valuable perspective on policy (Yanow, 2000). Attention to local actors and local knowledge seems to me an essential part of understanding what policy does, and therefore what it is. A classic interpretive policy analysis design would resemble ethnography of the stage that a rationalist view of policy would see as implementation. There is some cross-over with certain understandings of case studies of policy implementation, although there is little common ground with authors who foreground highly formalised case study approaches aiming at empirical generalisation and causal analysis (Gerring, 2007, p. 9). Accordingly I tend to use the term 'interpretive case study'.

However my research is distinguished from many interpretive projects by both my emphasis on interviewing over observation, and the way in which I recruited young adults for the study. I felt that interviewing, and not observation, should be my primary data collection method because I sought to dig down beyond the visible face of public involvement, and explore some of its absences. While the abductive approach requires a deep engagement with the social situation (Blaikie, 2000), it also rejects observation as sole method on the grounds that "a subjective experience can only be described by the person who has had it" (Chamberlain, 2006, p. 290). In ethnographic research, interviewing is often included only where observation is inappropriate or impossible (Bryman, 2004, p. 293). Interviewing is a more interventionist approach, in which the researcher creates the situation in which data is generated. This creates the risk that "respondents ... speak in uncharacteristically serious ways about issues that they usually treat flippantly, or ironically, or do not discuss at all" (Eliasoph, 1998, p. 19). However, I would argue that my concern with my respondents' sense-making requires more

concentrated attention than that available through merely observation or informal conversations therein.

Specifically, my research with young adults could not have been accomplished by observation because it was centrally concerned with their absence from public forums. This led to a formal approach to the recruitment of young adults which further distinguishes my research from many interpretive projects. Interpretive research tends to advocate letting the relevant 'publics' of a given policy identify themselves. In Yanow's seminal work on interpretive policy analysis, she describes her naturalistic approach in one study based around a community centre. This encompasses spending time 'mapping' the physical surroundings, reading locally-produced documents and surveys, talking informally with key contacts, and meeting and interviewing residents through being part of daily life in the area ("as I stopped at the greengrocers or other shops to buy lunch, posted letters, cashed checks, or stopped passers-by on the street to ask for directions when I got lost" (Yanow, 1996, p. 35)). As Yanow herself identifies, approaches based on snowballing: "may create patches of silent or silenced voices ... requiring additional purposive sampling to fill this gap" (Yanow, 2006a, p. 77). This acknowledges a role for the researcher which goes beyond simply reporting the 'out-there' existence of an issue, to one where the researcher defines/creates an issue and then assembles or summons the interpretive communities deemed to have a perspective worth hearing.

My focus on young adults (my choice of interpretive communities) thus requires additional justification. Given that the affected population in this case is simply an undefined 'public', with all the associated difficulties (Newman & Clarke, 2009), I focused the research on a purposively-selected subset; young adults. Largely absent from both public involvement mechanisms and research on them (Thompson, 2007), a focus on young adults was designed to "confront ourselves with just those things that would jar us out of the conventional categories, the conventional statement of the problem, the conventional solution" (Becker, 1998, p. 85). The conventional problem stated in existing literature is that staff members prevent or impede involvement by a generalised, idealised 'public' (M. Barnes, 1999; Harrison & Mort, 1998). In troubling the conventional category of 'the public', my focus on young adults seeks to question this conventional statement of the problem. Selecting a group likely to be in relatively good

health and often censured for its health-relevant lifestyle choices would, I suspected, trouble the conventional image of 'the public' and shed fresh light on the persistent search within community participation for 'ordinary' community members (Martin, 2008a).

My approach was to recruit interviewees through a formalised approach; sending letters to a random sample of young people on GP lists in my case study Community Health Partnership. Clearly this brings its own biases, not least attracting people who have specific complaints to share. However, registration with a GP is at least a reasonably universal feature of life in the UK. This is far removed from the ethnographic preferences of many interpretive researchers. However, as Yanow (2006a) concedes, simply immersing oneself in the life of a small community risks a bias towards those members of the public who play active, visible roles within their communities. My research sought young adults in a geographical area with high levels of deprivation and youth unemployment; so most likely not in full-time education, statistically unlikely to be active within community groups, and notoriously difficult to reach for research. My approach offered a relatively 'pure' sample, in that it did not resort to recruiting through youth groups or educational establishments. I contrast this with studies such as Marsh, O'Toole, and Jones (2007, p. 66) where recruitment through schools, colleges and youth projects and training schemes involved gatekeepers who in some cases "played a more interventionist role by selecting, and explaining our research to, potential respondents". The only criteria for inclusion were age and registration with a GP practice, which seems reasonable given the subject matter of the study.

Recruiting through the NHS required a clear and explicit definition of age range. In doing so I had to acknowledge the debate in child and youth studies on the inadequacy of age-based definitions of development. Age bands, although often used, are generally seen as very problematic (Hinton, 2008) and the concept of a transition to adulthood is generally preferred, expressing the gradual, complicated nature of growing up (Arnett, 2004; Furlong & Cartmel, 2007; Lister, Smith, Middleton, & Cox, 2002). In addition, major class-based differences in transitions to adulthood have been identified, suggesting that a working class 18 year old and a middle class 18 year old may be at very different life stages (G. Jones, 2005). While accepting the relevance of this literature, practical considerations demanded a more rigid approach, and I decided upon

19-25 year olds⁴. This was, firstly, because setting the lower limit above 18 avoids overlap with children's NHS services, in which issues of public involvement are subject to different rules. The more specific threshold also enables me to explore people who have been eligible to vote in an election,⁵ so that I can compare individuals' decisions and attitudes to representative democracy to those regarding consumerist and directly democratic means of influence. The upper limit was, however more pragmatic, largely following convention in similar studies (Arnett, 2004; G. Jones, 2005).

PILOT INTERVIEWS

A crucial stage in the refinement of my research design was interview piloting. I piloted my interview schedule for young adults with six individuals recruited from my own social networks in Edinburgh and Aberdeen. This model of recruitment meant that I was left with a more middle class sample than my eventual interviewees, but there was nonetheless much to be learnt from the experience. It helped to clarify the focus of the research, helped me to refine my interview schedule, and gave me invaluable practice in 'proper' interviewing (as compared to the very different experience of practising interviewing in a training context (Roulston, deMarrais, & Lewis, 2003)). Both my schedule and my interview technique came quickly unstuck in my early attempts. My first pilot interviewee was my sister, conveniently in the middle of the required age range and willing to cooperate for payment in tea and biscuits. I posed my first open question to a long silence. 'Em...' came the response, wide-eyed and desperately quizzical, 'like, like what?' This was repeated as my pilot interviewees struggled to engage with my questions.

In terms of my fledgling interview technique a somewhat naïve aspiration to give 'voice' to my interviewees quickly disintegrated. The more open the question, the longer the silence, the greater the confusion, and the more I found myself spontaneously listing possible answers. Few interviewees had the determination to reject all my guessed answers, and I was essentially adopting the multiple choice approach which I rejected in favour of seeking the full richness of my interviewees' descriptions. My interviewees'

⁴ More specifically, people who were born between 1st May 1984 and 1st May 1989.

⁵ Namely, 2007 Scottish parliamentary and local government elections.

lifeworlds rarely had a chance to be articulated. Weiss (1994, p. 37), reflecting on a colleague's similar interviewing style, attributes this to impatience, but I feel it came from a misguided attempt to make the interview easier for my interviewee. Through practice I have become better at sitting quietly and being less present within the interview encounter, but I still have to resist the urge to reframe and specify my questions until they visibly 'click' or connect with something meaningful for my interviewee. As a researcher, giving your interviewee space to express themselves is asking them to do a lot of work; unless the topic of the interview is within what they recognize as their field of everyday expertise.

This leads on neatly to the problems with my initial interview schedule, drafted while immersed in the discourse and literature of public involvement policy. Piloting first revealed what has since become a major focus of my research; the gap between young people's lives and the formal institutions of public involvement. Not only had none of my interviewees heard of opportunities to influence the NHS, asking about them (however tentatively) made some interviewees nervous, apologetic or silent. In this sense, their non-participation related both to formal mechanisms of involvement *and* to our interview. While remaining physically present in the interview, their withdrawal was remarkable. This 'finding' was temporarily discouraging. However, as this chapter will describe, in the long run it reoriented my research in a productive way. With a better interview schedule and an improving interviewer, the essential focus of my research project could be re-envisaged, not redesigned.

DATA COLLECTION

CHOOSING RIVERMOUTH: CASE SELECTION

Unlike positivistic approaches, interpretive research does not seek empirically generalisable results (Yanow, 2006a). The alternative goal of theoretical development relies on a full and deep knowledge of the case, enabling commonalities to emerge from ostensibly differing accounts of experience, rather than an explicit strategy of generalisability. This means that the selection of a particular case study location need not adhere to the demands of, for example, Yin's (2003) account of case study selection. Instead, my choice of CHP and then of GP practice was purposive; a practical decision

incorporating theoretical considerations. Given the very small numbers which were practicable for this study, the emphasis on theorising rather than statistical adequacy which purposive sampling offers (Weiss, 1994) was an appropriate choice.

Selecting a single CHP was guided by a combination of practical and intellectual considerations. Practically, given the time and financial constraints of a PhD project, I felt that my case study site should be within a 2 hour drive of Edinburgh. Research funds could not cover frequent overnight stays, and I wished to be able to visit as often as possible. Intellectually, I sought a CHP that was neither urban, nor remote and rural. These two extremes have specific consequences for dynamics of local health services in Scotland (Woods & Carter, 2003). A middle ground is offered by areas with a medium-large 'county town' and a surrounding hinterland. The town of Rivermouth (population circa 40,000) is a population centre for Rivermouth CHP. I was also interested in studying somewhere that would allow me to explore differences around social class and participation. The relationship between deprivation and community engagement is not straightforward (Pattie, et al., 2004). However, the critique of public involvement as a middle class pursuit is influential (House of Commons - Health Committee, 2007), and I was keen to explore dynamics in an area with significant deprivation. Rivermouth has particularly high levels of deprivation for a non-urban location, and has one of the highest proportions of Jobseekers Allowance claimants in Scotland (as reported in Scottish Public Health Observatory, 2008). Purposive sampling was likewise used for selecting the GP practices through which I recruited young adults. Scottish Primary Care Research Network staff wrote to all GP practices in Rivermouth outlining the modest demands of the research and explaining the financial and practical support available for participation. Five practices responded. After discounting one practice with a very small patient list (raising issues around guaranteeing anonymity but also practical issues around the number of young adults available on the list) I selected two which varied most in terms of practice location (town centre or village) and population deprivation (through the profiles available at www.isdscotland.org). This was intended to maximise the potential diversity within my sample.

NEGOTIATING ACCESS AND FORMAL ETHICAL APPROVAL

Buchanan, Boddy, and McCalman's (1988) characterisation of organisational research as 'getting in, getting on, getting out and getting back' highlights the social processes involved at every stage of research. I spent around a year researching Rivermouth in total, from first meetings to last feedback to the PPF. At its most concentrated I was visiting three or four days a week, although for most of the time it was perhaps once a fortnight. My fieldwork coincided with one of the coldest winters in decades, and my memories are dominated by anxiety about my car starting, the locks freezing, and black ice on the roads. Due to the unexpected delays of NHS approval, the most intense period of fieldwork (between November and February) coincided with very short daylight hours, and this meant that much of my interviewing in young adults' homes involved arriving in half-light or darkness. The experience of fieldwork seems unusually composed of highs and lows; moments of high excitement (frequently while sitting hunched in the car scribbling down thoughts on an interview) and of frustration and anxiety (about a challenging interview, or an appointment cancelled at the last minute). Even without the commitment of an ethnographic approach – I lived in Edinburgh throughout, travelled home each night, and kept a separate mobile phone for research contacts – fieldwork is an absorbing process. The combination of uncertainty about one's own abilities, uncertainty about one's own project (which as discussed below was changing during fieldwork) and absorption in a solitary task which required daily smiling, encouraging contact with strangers is a difficult combination.

While I characterise my fieldwork as organisational, Rivermouth CHP was a fluid sort of organisation. CHPs exist in a 21st century fashion, as logos, letterheads and website, but as a sub-organisation within Health Boards, are minimally located in the physical world. This is an acknowledged challenge that is not specific to Rivermouth: a recent Audit Scotland review raised concerns that CHPs "did not come with the necessary authority" and that "there is now a cluttered partnership landscape" (Audit Scotland, 2011, p. 4). I interviewed and observed across a wide spread of buildings, and my presence collecting documents, observing meetings and requesting interviews within the CHP probably went unnoticed by most people whom I did not approach to interview. When observing the CHP Committee (held in public but with very few public attendees) the Chair introduced himself and I explained I was a student doing research. He seemed

unconcerned and my general sense was that my research was unobtrusive for the wider organisation.

However, the inclusion of research with young adults required engaging with the hyper-formalised gate-keeping of the Medical Research Ethics Committee and NHS Research and Development. The frustrations of this occasionally opaque and consistently onerous process have been well-documented by other researchers (Elwyn, Seagrove, Thorne, & Cheung, 2005; Thompson & France, 2010). These procedures are designed for biomedical research and their response to social research is haphazard. Without the support and advice of colleagues who had recently gone through the process, and particularly the staff of the Scottish Primary Care Research Network, this six month process could easily have taken longer. As it was, the project was designated as 'service evaluation', not research; the committee's only comment was that I would probably struggle to find any GP practice interested in cooperating. Written confirmation of this judgement had to be provided to the local NHS Research & Development office before the project could proceed but, in a Kafka-esque fashion, this confirmation does not constitute ethical approval; in fact it merely confirms that I should not have sought ethical approval. The bright side of this process is that the practicalities of my research with young adults were meticulously planned in advance of entering the field. The delays and intricacies of the MREC process, while not guaranteeing consideration of the genuine ethical dilemmas which can occur in the field, do certainly create time and space in which to consider potential problems and make decisions about their handling.

Research ethics, as formally defined, were predominantly concerned with the recruitment and interviewing of young adults. GP practices were asked to screen out any participants who lacked the capacity to give informed consent. A two-stage process was then used to ensure informed consent. Participants were sent a recruitment pack containing a written information sheet before expressing a willingness to be interviewed by returning a short form in a stamped addressed envelope. Interviews began with a careful discussion of the consent form and the opportunity to ask questions about the research before signing the written consent sheet. I was concerned throughout that not just risk but inconvenience to participants be minimised. Arrangements for the time and place of interviews were made entirely at the interviewees' convenience.

In lieu of childcare or other costs, young adult interviewees were offered a £10 supermarket voucher in return for their time. This was given at the start of the interview to make it clear that it was not conditional on the content of their responses. None of my interviewees commented particularly on the voucher, with the exception of Sarah (whose mother took it) and Lauren, who exclaimed “I’m after drink with it”. The literature on financial inducements offers a mixed picture of its ethical consequences, but there is some degree of consensus that modest payment is unlikely to render otherwise acceptable projects unethical (Toumbourou et al., 2004; Wilkinson & Moore, 1997). In this case, I felt it was unethical to ask people in an area of high unemployment and deprivation to give their time for free when the interview was likely to offer them few advantages. Unlike both NHS staff and participants, who might reasonably be assumed to gain from either discussing or hearing research findings on public involvement, young adults were being asked to discuss firstly remote policies with little relevance to their lives and secondly their personal health and experiences of health-care. Other than the ethical dimensions of this decision, thought must be given to its consequences for my response rate. Research on surveys (both telephone and postal) has concluded that offering financial inducements “consistently and substantially” increases response rates (Singer, Van Hoewyk, & Maher, p. 171). While this is clearly only one reason why an individual would respond to an interview request, it seems likely that the effect of financial inducement varies along with the income of respondents (Weiss, 1994). This suggests that my offer of a voucher might have disproportionately increased the responses I received from young adults living on low incomes.

RECRUITMENT

For organisational perspectives on public involvement I conducted desk research to identify the key local actors within Rivermouth. This led me to three individuals: Pat, the lead officer for the Local Authority youth engagement programme; Jennifer, the Patient Focus Public Involvement 'lead' for Rivermouth and coordinator of the Public Partnership Forum; and William, a local officer for the Scottish Health Council. I contacted these three people by email, and snowballed from this point on. Every staff member I contacted agreed to be interviewed (although my several attempts to request interviews with the local Members of the Scottish Youth Parliament failed). The

community of staff working on these issues was small, and recommendations for other staff to interview were largely consistent across the group. For example, all three suggested I interview Donna, who was seen as the key practitioner in NHS youth engagement locally. Differences were interesting. For example, Richard suggested I contact the Board's equalities lead, but no-one else identified her as a key actor in public involvement. This supports the argument I develop in chapter 4 that there were multiple groups of staff pursuing alternative visions of public involvement. PPF members were recruited in person at meetings.

The process for the recruitment of young adults was appropriately more complicated. The SPCRN coordinator visited the two practices to meet with staff and supervise the creation of a sample of around 200 suitably aged patients. This list was checked by all partners to remove patients who should not be approached. This section of the process was out of my hands; practice A removed 15 patients and practice B less than five. At practice A, this number mostly consisted of patients with Eastern European names; this was unfortunate in terms of the diversity of my sample, but was a decision made by practice staff for reasons of language. Along with a SPCRN staff member, I attended the practice to oversee the mail merge to create recruitment letters and help to add these to pre-assembled recruitment packs. At no time was I given access to the database of patient information, nor was the list of names or any other patient information removed from the practice.

Aside from the practicalities of this process, the social dynamics of recruiting through GP practices were interesting. In practice A, envelope stuffing was done in a busy, cramped staff area. While most staff were helpful and friendly, two incidents threatened the project. First, on the day of the mail-out one of the GP partners expressed vehement disapproval of the project (despite having previously approved it along with the other partners) and requested that letters be taken off the practice letter-headed paper. The practice manager helped us to overcome this problem and signed the letter herself. Several practice nurses also came to observe the process, offering a running commentary on the patients we were contacting ("she'll never reply!"). Staff were openly sceptical about the research, and the GP partner was hostile. By contrast, at practice B staff were friendly but (with the exception of one partner who was out of the building on the day of the mail-out) uninterested in the project; we were given an empty

consulting room to work in and left alone. The support of the SPCRN staff member entailed that this did not influence the mail out of recruitment packs. However, had I been alone I may have found it more difficult to continue, and to ignore the suggestions of staff that certain interviewees were lost causes. Considering the varied sample of interviewees I eventually managed to recruit, including several individuals who would likely have a poor reputation within their practices, I am glad that I persevered. These experiences gave the impression that public involvement was not a priority for many staff within these two practices, and that for one GP it was seen very negatively as a distraction from core business.

Once interviewees had returned the form indicating a willingness to be interviewed, the process of arranging actual interviews, completely overlooked in my planning, proved particularly difficult. I initially expected many responses to be from people with a specific grievance regarding the NHS, but in the end this only seemed to be true in perhaps three cases (Lisa, Lauren and Sarah). The supermarket voucher for participation is likely to have contributed to less 'partial' responses. In several cases, my interviewees were unemployed or at home with children and bored, and happy to have something different in their schedule for the day. Several described themselves as the sort of person who fills in things like this. However, most seemed to have returned the recruitment questionnaire on a whim (several having no recollection of having done so), and required quite intensive follow-up in order to complete an interview. This stage of recruitment is rarely discussed in methodological accounts of qualitative research, and yet I found it full of delicate decisions, partly as a result of the range of possibilities for communication. Most interviewees had given only a home address and a mobile phone number for contact details. Every few days I would call all respondents (keeping note of the time, date and mode of contact). The peculiarities of mobile phone contact started worrying me. Mobile phones would show multiple missed calls; a record of my repeated attempts at contact. I started to feel, as I put it to my supervisors, "like a stalker".

Frustrated as potentially viable respondents proved uncontactable, I resorted to text messaging. In my own social life, almost all events are arranged via text message, or online communications; I rarely speak to any friends on the phone. Text messages can be picked up silently at work or at one's own convenience. I quickly found that the monosyllabic conversations I had with most interviewees on the phone flowed more

freely, if more slowly, in text messages. Communication was transformed, with one hitherto unresponsive participant routinely ending each message with a casual 'x'. Both of us had a written record of what was suggested and agreed. The biggest difference was with male interviewees. While my preference was to make contact by text message and then schedule a phone call to arrange the actual interview, this did not always work out. Every interview with a male respondent ended up being arranged entirely via text message. There are clearly drawbacks to this approach. I felt more nervous going into an interview with someone I had not spoken to. It is difficult to detect tone in a text message, and so I occasionally thought people were more enthusiastic or less confused (and thus less in need of explanation) than it turned out they were. All arrangements were, of course, confirmed in advance of the interview by standard letter, enclosing a consent form, but there was potential for confusion. While responses were often very informal, I had to remind myself to take time to compose appropriately professional text messages, while keeping within the conventions of the medium regarding length and tone. I tried to take my cues from the messages I received from each individual, avoided all but the most common of 'text speak' and always began "Hi " and signed off "Ellen".

It was always anticipated that response rates for this section of the study would be a problem. This was intrinsic to the aim to interview people with little or no experience of the topic under investigation. Of the 400 letters that were sent out, 22 replies were received, and 14 interviews were conducted. A particular problem was the recruitment of men, with only three males in the sample of young adults. I had initially hoped to interview around 30 young adults, with a more even gender split. I had also hoped to interview more people in full-time education. When it became apparent that I was not going to reach 30 interviewees, I considered a number of strategies to try to increase numbers. I had tried to snowball through existing interviewees, by leaving recruitment packs with them, but this did not result in any responses. In retrospect, adopting a more informal approach (for example where an interviewee's partner was in the house, asking them to sit down for an interview right away) might have been more helpful. However, I was very conscious of the ethical consequences of such an approach, particularly given the formal involvement of the Scottish Primary Care Research Network in recruitment. To be clear, I do not think this would have been an unethical step, but it would have involved collapsing the three-stage informed consent process to which I had committed in my Medical Research Ethics Committee protocol.

I also considered recruiting through non-NHS routes. I asked a local college to put a request for participants on its intranet, but again this method failed to get any responses. I did not ask my contact there to make any direct approaches to students. This was because much research on young adults recruits through youth groups, community organisations or schools and colleges, where gatekeepers may skew the resulting group of participants by selecting 'co-operative' participants or 'those who will have something to say'. Marsh, O'Toole, and Jones (2007, pp. 65-66) discuss the role of proactive gatekeepers in their study recruitment, admitting that in several cases gatekeepers selected the participants, and that one actually "posed" as a respondent to take part in a focus group. For the purposes of this study I would argue that the demographic differences between young people are not necessarily any more relevant than the differences between a young person who plays an active role in community organisations and one who does not. In drawing conclusions from their demographically balanced but experientially skewed sample, I feel Marsh, O'Toole, and Jones (2007) compromise their findings more than they acknowledge, and suspect this might contribute to their finding such "forceful" views about politics. Thus, while my sample is certainly imperfect, I remain confident that my decision was appropriate for the particular focus of this study.

INTERVIEWING

Interviewing is close to being the default method for qualitative research, and is an increasingly common part of society more broadly (Gubrium & Holstein, 2003). The category covers a broad range of approaches, and descriptors vary, with commonly used terms including depth interviewing and simply qualitative interviewing (Weiss, 1994). I follow Bryman (2004, p. 318) in finding the three categories of structured, semi-structured and unstructured a useful framework, although in practice these can be fluid descriptors. Semi-structured interviews were intended from the earliest stages to comprise the bulk of my data collection. 32 semi-structured interviews were conducted: 14 with young adults, ten with members of the PPF past and present, and eight with NHS and local authority staff. This emphasis on interviewing was intended to ensure that the primary focus of the research was on local perceptions, rather than my own views. Having rejected a purely observational project, interviews seemed to offer what Kvale wryly caricatures as: "A personal alternative to the objectifying positivist quantification

of questionnaires and the harsh manipulations of behaviourist experiments” (Kvale, 2006, p. 481).

However, views on the voice-giving or emancipatory potential of qualitative interviewing vary, and in some of the literature appear to be entirely polarised. As Sinding and Aronson (2003, p. 95) observe: “At one extreme, interviews allegedly empower ... at the other, they draw reproach for feigning intimacy with, and then abandoning, the people they engage”. Attempts to give voice through interviews are critiqued as naïve on two grounds. It is argued firstly that researchers cannot operate merely as a channel – a “pipeline” (Oakley, 1981) – for the stories of their interviewees. Post-modern approaches assume the existence of multiple realities (Schutz, 1945) and accordingly conceive of the interview as a “mutually created story” (Fontana & Frey, 2000, p. 645) not report of fact. In an active interview, interviewer and interviewee together construct meanings relevant to the research question, within the context of social “conditions of possibility” (Kvale, 1996). Thus, an interview cannot be seen as an unmediated opportunity to access the ‘truth’ of the research subjects. Secondly, it is asserted that in the process of depth interviewing there is potential for damage to research subjects: involved or close methods create intimacy with the potential for both manipulation and betrayal (McDowell, 1992). At extremes, the good intentions of researchers are seen as a Trojan horse (Kvale, 2006, p. 482), and a cynical means to a selfish end (Briggs, 2003, p. 244). Ultimately, it is argued, it is researchers, not their subjects, who benefit from interviews (Kvale, 1996) .

I find the former set of arguments convincing, and the second worthy of attention, but neither negate my preference to interview the people I study. Instead, they inform my interviewing practice. One of the most trenchant critics of standard interviewing practice supports an improvement, not a rejection, of interviewing in research (Briggs, 2003). Interviews “are in themselves neither ethical nor unethical, neither emancipating nor oppressing” (Kvale, 2006, p. 497). The powers and vulnerabilities created by an individual interview lie largely in its aims, its planning, and its practice within a social context (K. E. Smith, 2006). Throughout my fieldwork I aimed to minimise any risk to my interviewees. One-off interviews are less likely to create artificial or unsustainable bonds of trust; and care was taken to respect the needs and preferences of interviewees at every stage. Attending to my interviewee’s body language and long pauses, if

questions or areas of discussion seemed to be uncomfortable I would not probe further. These are inevitably imperfect, improvised decisions where one is conducting a one-off interview as a stranger. At times this leaves blanks within accounts which I wish were filled – as with Lisa’s reluctance to talk about her experience of (NHS) community drugs services – but in each case I felt it was more important to respect my interviewee’s privacy than ask for more detail. When difficult issues arose, or interviewees became emotional, I expressed concern while trying to stay mindful of my position as a stranger and a researcher (Weiss, 1994, p. 128). However I was often surprised by my interviewees’ openness. I found that with young adults, discomfort was more often about being asked ‘why’ questions (as Becker (1998, p. 58) puts it, implicitly asking for a rational account) than about describing intimate bodily issues. Interviewees were told they could retrospectively request any part of the interview to be removed from the analysis, but none made such a request.

In terms of methodological interest, my research design has the advantage (although it rarely felt like one) of including interviews with a wide spectrum of society about their different roles. There were many differences between these groups of interviews. One was a difference of location and costume: cluttered hospital offices, tidy suits, and mugs with out-of-date NHS logos on; formal sitting rooms, neat cardigans, cups, saucers and shortbread; a hastily cleared corner of a sofa, pyjamas and music TV blaring. A further difference between the groups of interviews was in the ease and comfort with which interviewees answered my questions. Despite changes to my young adult interview schedule after piloting, it was clear that my questions relied upon discourses more familiar to some interviewees than others. This illuminated how detached the terminology of these policies had become from any ‘common-sense’ meanings. For staff, a question about involvement conjured up particular documents from Central Government, other linking or conflicting policy agendas, meeting rooms and committees, perhaps a buffet lunch they need to order for next week or an unanswered email sitting in their inbox. For ‘ordinary’ health service users it was essentially meaningless, unfettered, empty. ‘How would you like to be involved in the NHS?’ In what? Doing what?

In this section I discuss the practice of interviewing within this research project. It divides, as did so much of this project, into reflections on interviewing staff, participants

and young adults. However, the essential approach was the same throughout. In my 'role' as researcher I went to my interviewees' preferred locations (whether work or home) and dressed consistently in what I hoped was a neutral outfit: plain black trousers (not jeans), a plain long-sleeved T-shirt and a short-sleeved cardigan. In the early days of fieldwork I gave careful thought to this, but as time went on it became routine. In retrospect, I sought to be ageless and classless, and undoubtedly (as will be discussed) failed in both quests, but there was at least consistency in how I physically presented myself in the field. Each interview began with me explaining the broader study and asking if the interviewee had any questions. I talked through the written consent form, and the interviewee and I both signed two copies. The interviewee kept one and I the other. I audio recorded all but two of the interviews. In two cases the interviewees preferred not to be audio recorded (both saying that they did not like to hear their voice on tape) and so I took thorough notes and incorporated these into the analysis.

STAFF INTERVIEWS

Interviews with staff members were conducted in their offices or in meeting rooms. I worked with a basic interview schedule which I customised for particular interviewees. All interviews covered interviewees' roles and responsibilities, their understanding of public involvement in the area, issues of diversity in public involvement, and the involvement of young people. Some of these interviews were long and interesting discussions which revealed a lot about the local 'assemblage' of public involvement. Others were brief, merely signposting me on to a more relevant person, or pointing me to documents or websites. In all of them, responses came quickly and easily. The managers I interviewed spend their days reading and writing documents about and planning meetings and events for the purposes of 'involving' and 'engaging' various combinations of 'the public' 'the community' and 'hard-to-reach groups'. At times their answers were rehearsed, full of jargon, on the tip of their tongues. Sometimes I hardly had to ask a question, but just introduce myself and my project and let them speak. Then I could try to unpick some of this. 'What do you *do* when you are involving people?' 'What does a day of working on engagement consist of?'

PUBLIC PARTNERSHIP FORUM MEMBER INTERVIEWS

These interviews, conducted in the homes of the PPF members, were among the longest and most congenial. Interviewees (or their husbands or wives) showed me to a seat, offered me a hot drink and presented me with an array of cakes and biscuits. I felt like a guest, come for a gossip. This contrasted with most of my interviews with young adults, where I was shown in and felt, at least at first, like an inspector or teacher. The geographical location of these interviews took me outside the two small pockets of the CHP where I interviewed young adults. Several were located in the far east of Rivermouth CHP, where the post-industrial poverty of central Rivermouth borders the leafy seaside villages and holiday homes of the more affluent neighbouring CHP.

One reason for the length of these interviews was the amount of ground covered by the schedule. Interviews covered recruitment into the Forum, what members saw as the Forum's role and their part in it, whether they would change anything about the Forum, whether they felt members represented the public and what they thought about (the absence of) young people on the Forum. Tales of how members came to join the PPF started with explanations of their own health, or that of people they cared for, and then developed into a gradual engagement with the work of committees and consultations. They tended to bridge the realms of personal health and illness and the governance of the NHS: these moments, although central to the topic under investigation, were rare within this fieldwork overall. Most interviews were relaxed and easy. I had met all of the interviewees at meetings before the interview and I knew several of them quite well. Having observed multiple meetings, I several times found myself being quizzed as much as quizzing. Newer members of the Forum, who were figuring out its operation at the same time as me, repeatedly asked questions about how members were meant to 'do' involvement. In most cases I did not respond, simply nodding or shrugging to convey general puzzlement, but in one case I had to ask the interviewee if we could discuss my thoughts after the interview. We then, after the tape was switched off, sat down to lunch and I explained a bit about the background to my research, although I said it was too soon to draw any conclusions about the PPF.

YOUNG ADULT INTERVIEWS

Interviews took place in the interviewee's home in all but one case (David was interviewed in his workplace, after his working day had ended). These were more challenging interviews, requiring coaxing and more input from me than others. One review of Eliasoph's (1998) ethnographic account of political apathy characterised her

research as “listening to the silence” (Bellah, 1998): I always think of these interviews as ‘prodding the silence’. These interviews were rooted in accounts of how interviewees interacted with health services. The young adults I spoke to weren’t aware of being ‘uninvolved’ or ‘disengaged’ (or, for that matter, ‘hard-to-reach’). These were not meaningful terms for them. I started by building a broader picture of young adults’ health service use and political participation in the context of their lives, focusing on what *is* meaningful and relevant to them. I also asked what they would do, or who they would talk to, if they were unhappy about any health service interaction. From this baseline, if they had not been mentioned, I introduced a more hypothetical discussion about moments of agency within the NHS: complaining about service failures, joining a Public Partnership Forum, or choosing an alternative service provider. While schedules for all interviews are included in appendix 3, I adhered more strictly to the schedule for my interviews with young adults. For the section covering public involvement, I read the questions verbatim in recognition that my questions here did not merely generate answers, but in most cases generated an awareness of the mechanisms of public involvement for the first time.

The category of young adults conceals considerable diversity and my interviewees were a mixed sample, reflecting the diverging trajectories of life in this age group (see table 4). They covered the full age range of 18-25. One was a university graduate and one a university student. Several were full-time mothers. Three were unemployed and the same number were on Government training schemes for the long-term unemployed. Those with jobs mostly worked locally in the service industry, except for one recently qualified professional who had returned home to live with parents after qualifying. In chapter 6 I do not differentiate my interviewees by characteristics; there were strong commonalities in most accounts and this study does not attempt to demonstrate correlations for generalisation.

However, health status, gender and class were relevant differences within the sample which should be acknowledged. I struggled to recruit young men for the study. Those who took part reported less frequent experience of health services (although they reported fairly serious incidents of accidental or violent injury), and generally expressed fewer strong feelings about health services. Connell argues that while some ‘sex differences’ in men’s and women’s health are well established by multiple studies,

others are likely to be exaggerated by the consistency of sex/gender as a routine variable: “this does not require any specific thought about the nature of gender or the meaning of gender difference – that is typically taken for granted, or vaguely assumed to be a biological distinction” (Connell, 2000, p. 180). It is important to acknowledge that the ‘risk-taking behaviours’ my male interviewees reported can be understood as “a classic case of collective gender practice” in which a peer group both shapes and responds to existing norms of ‘masculinity’ (Connell, 2000, p. 185). Willingness to discuss one’s health or admit views on health services (with a female stranger) are similarly gendered behaviours (Courtenay, 2000).

Table 4: characteristics of young adult interviewees

Characteristic	Number
Men	3
Women	11
In work	7
In full-time education	1
Unemployed	3
On a Government training scheme	3
Total interviews	14

In terms of health status, several of my interviewees had long-term health conditions for which they were receiving treatment through dedicated clinics or community teams. While this gave them a broader range of experience of the NHS, I was surprised at the extent to which their experiences of GPs and their GP practice resembled that of my ‘healthier’ interviewees. Finally, social class was a dimension of difference. Literature on youth transitions to adulthood continues to assert the relevance of class differences (Furlong & Cartmel, 2007) despite an influential body of work arguing for a more unified experience of transitions to adulthood in the risk society (Arnett, 2004). My interviewees were mostly from working class backgrounds. The two interviewees who were university educated did discuss their GP practices with more confidence and assertiveness than some other interviewees, but this was not a clear-cut category. Other factors, including living within the parental home and having close relatives or friends who worked within the NHS, also seemed to influence this.

OBSERVATION OF THE FORUM

The observation of the Public Partnership Forum was not planned as a major component of the research project. I first planned to attend one meeting to introduce my research, get a sense of how the PPF functioned, and recruit a small number of interviewees. However, I found meetings intriguing, so asked whether I could continue attending. By the end of my fieldwork I had observed five regular meetings and attended two additional events with PPF members. My interest was driven by a puzzle scribbled in the field notes of my first meeting 'what are these people doing here?' This question arose both literally (what is the nature of this activity?) and colloquially/incredulously (why have they chosen to give up their time for this?) The combination of observation and interviewing was a powerful one, enabling me to get at a level of meaning somewhere between the physical happenings of the meeting (turning the pages of papers; raising one's hand to speak; asking for clarifications) and the assumed significance of the practice as a whole (each meeting was in some way, as a visitor to a meeting put it, 'doing' public involvement). I see observation primarily as informing my interviews. As it turned out, it helped me in securing interviews with members but also vastly improved their content. Members had met me and so were more open, we had some shared experiences to discuss, and I could ask what they thought of particular occurrences in meetings, testing out my interpretations. I also found attending the PPF an enjoyable experience, reflecting literature which highlights simple enjoyment as a key part of why such voluntary groups persist (Roberts & Devine, 2004). Members were welcoming: almost all extended an open invitation to me to drop in when I was doing fieldwork in their towns and villages. Meetings, although, as chapter 5 describes, lacking the shared purpose I had anticipated, were pleasant events with laughter and good humour. I learnt fast about how the NHS does business at this local level, starting to read through the templated papers to the content within, and getting to grips with the endless acronyms scattered through them.

The extent to which this constitutes participant observation remains unclear. Gold's (1958) frequently cited classification places observation on a continuum of involvement/detachment from complete participant, participant-as-observer, observer-as-participant, to complete observer. Debates as to the formal benefits of different modes of observation (Bryman, 2004, p. 302; Moug, 2007) seem to me to bear little resemblance to how research develops in the field; following Gans (1968), I would argue

that my role shifted back and forth across the period of fieldwork. I was treated like a member of the group, with a nameplate waiting for me on the table and papers sent to me in advance along with members. There was an unspoken agreement that I would not contribute to the formal business of meetings, but I was undeniably present. As I got to know members better, several would mutter comments to me under their breath, or ask me for clarifications when confused. In the tea break, I helped dole out cups of tea (taking on some of the labour of the meeting), and then wondered, too late, whether this was over-stepping the observer's role. Perhaps, I wondered, I was meant to refuse the offer of tea at all. Observation is something to be constantly negotiated (Bryman, 2004). What was lost from my research by chatting to members, tidying tea cups and helping members find the correct page of a paper was, I would argue, gained in the easy relationships I developed with them. Perusing papers along with members might have meant I missed details in observing, but it educated me in the content of meetings, and helped me to comprehend the jargon of interviews.

RESPONDENT VALIDATION

Respondent validation – the provision of an account of research findings for feedback from research participants (Bryman, 2004, p. 543) – is not a straightforward matter. While it is often seen as an essential tenet of good qualitative research (see for example Creswell, 1998), Angen argues that the practice relies on “the foundationalist assumption of a fixed truth or reality against which the account can be measured” (Angen, 2000, p. 383). I understand respondent validation not as a way to test the ‘truth’ of my interpretations, but to explore how they are received by my research participants, as well as a simple courtesy for people who have shared their time. I intended to offer an opportunity for dialogue, and to offer up my findings as, if not “emancipatory resource” (Bauman, 1976), a helpful external perspective. In this project I did not encounter any opposition to my findings, but neither did they appear novel or illuminating to participants. I conducted separate respondent validation for young adults, and staff and the PPF. Young adults were sent a summary of our interview and a summary of my findings more broadly. Several responded to say ‘that’s fine’ but most did not, and none offered any thoughts or clarifications. I also wrote a brief paper, loosely based on sections of chapter 5, and distributed it to the PPF members and staff.

As chapter 8 demonstrates, I have modest hopes that my research at least has the potential to demonstrate “correspondence between ‘scientific’ and commonsense thinking” (McKeganey & Bloor, 1981, p. 67) , but in the paper for the PPF I struggled to articulate a level of analysis between banal description and theoretical abstraction. This tension was difficult to resolve within a single document. As both respondent validation and requested feedback – which also needed to be comprehensible to those less comfortable with written material – it required careful drafting. I attended a final meeting of the PPF to talk through the paper and answer questions. I chose the material on diverse views of the purpose of the Forum and demands of membership, and tried to write a sensitive account, with no quotes or identifiable information about which members told me what. I hoped that this would give voice to some of the dissatisfaction I heard about from quiet or newer members, without upsetting the Chair or Jennifer. This brings to mind Bloor’s description of the difficulties of conducting respondent validation in the context of “fondness and mutual regard” (Bloor, 1997, p. 236) between researcher and research subjects. In doing so, I suspect I stripped my findings of any interest, and while no-one expressed any disagreement, the response was muted and polite. One member asked simply for an evaluation of the Forum: “are we getting there?” At the time I said I wasn’t in a position to answer, but in retrospect the correct answer, with the potential to start an interesting conversation, would have been “where are you trying to get?”

IDENTITY IN THE FIELD AND PERSONAL SAFETY

Reflexivity in the field is now commonly accepted to be a critical part of all qualitative research (Finlay & Gough, 2003; Hertz, 1997) . One senses that subjectivities are often, as Law and Lin (2010, p. 137) argue, seen as “a diversion, (or light relief) at best and a sign of self-indulgence at worst”. I have attempted to integrate reflexivity into the planning, conduct and writing up of my research project, but one specific point to highlight concerns my identity in the field. I found my identity as a PhD student – more serious than ‘a student’ and considerably less intimidating than ‘an academic’ – useful in the field. Avis (2002, p. 199) describes the search for a research identity, stating: “I was not sure who I was in those interviews, and assuming a role as ‘expert’ potentially offered a route out of that uncertainty”. By contrast, in the field I liked being ‘a student’. Interviewees expressed concern for how I was getting on in ‘my course’ and asked when I would finish. The presence of this other purpose in the interaction (helping me to get a

qualification) took the pressure off the search for knowledge, and I think this was a relief for interviewees as well as for me. Bhavnani describes the dimensions of her identity (including age, class, ethnicity and gender) along which power or powerlessness could be read in the field. In my case, the relevance of these varied in the component parts of the research. With staff and participants I was mostly of a similar social class, but younger. There were occasional moments of awkwardness in the PPF, such as when I realised in a meeting on Armistice Day that I was the only person in the room not wearing a poppy, but this was a tolerant, friendly group, who were initially intrigued and then increasingly uninterested in my presence. The only staff member who was around my age was Donna, a youth engagement specialist in the health improvement unit, who was occupied with similar research. Far from establishing a relationship of competition, as described by Weiss (1994, p. 139) when interviewing another academic, our interview was long and congenial, and followed by sharing of suggestions for our current research projects.

With the young adults I was the same age or slightly older, and undeniably middle class. However, the embarrassingly decrepit state of my car helped me to feel less like a colonial ethnographer of old (more than one interviewee helped me to unfreeze the locks at the end of the interview). Interestingly, with those interviewees who had children I felt young and ignorant; their socially-sanctioned expertise about bodies and illness seemed to 'trump' my academic status. This was less prevalent with other young adult interviewees, although the shift in interview into a focus on their everyday health and service use helped mitigate this. While attention to one's demographic characteristics is to be commended, questions of status remain unpredictable in research, due to the "hybrid and multifaceted nature of power" (K. E. Smith, 2006, p. 644).

The formal requirements of NHS Medical Research Ethics Committee approval had required me to give more thought than I otherwise would have to my own safety in the field. The main concerns here were around the interviews with young adults, because these were with strangers, and conducted in their own homes. Following advice in Craig (2005) I recognised the unpredictability of risk but put reliable systems in place. For every such interview the address I was going to was left with my partner, who I would phone or send a text message to on leaving the interview. If I did not get in touch within

one hour of the appointment, he would call my phone. In practice there were only two incidents in the field where I felt uncomfortable or in any way at risk. The first was my interview with Sarah. On arriving I was shown into a small living room in which her parents and older sister were all sitting. It became clear that, despite me adding “So Sarah” to the start of every question, the interview was going to involve the whole family. Given the size of the flat (two further siblings were in the bedrooms) there was no other space where I could suggest we move for a more private interview. This family had moved to Scotland in search of an area with fewer immigrants or ethnic minorities, and they were keen to expound upon this topic at length. Sarah’s father wanted to know more about me, and my reasons for conducting the research (“you don’t sound Scottish” “how much are you being paid for this?”) Having finished the brief discussion with Sarah I sat and listened to the increasingly unpleasant views of the family for around 30 minutes, with my attempts to leave ignored or rebuffed. Being white and ‘British’ I was not being threatened, but it was a difficult experience nonetheless. I was glad to get to away. On a second occasion, my interview with Ryan, I found his flat in a run-down tower block, and he met me at the door. Ryan is heavily tattooed, shaven-headed and into weight-lifting, and my prejudices about his appearance made me nervous. As I walked ahead of him into the flat he switched off the hall light, leaving us in total darkness until I found the door to the living room at the other end of the corridor. A moment’s panic passed quickly when he apologised, explaining that he and his brother were running low on money for the electricity meter, and this went on to be a really enjoyable interview. On both of these occasions I was reassured by the procedures I had set up to keep me safe. On my drive back to Edinburgh I stopped at Rivermouth’s out-of-town shopping complex for a cup of tea. This space, local to Rivermouth yet familiar from similar developments all over the UK, was where I took “the extra time to return from the respondent’s world to my own” (Weiss, 1994, p. 125).

ANALYSIS AND WRITING UP

DATA ANALYSIS

My approach to data analysis most closely resembles that contained within grounded theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1997). Bryman (2004, p. 401) summarises it thus: “two central features of grounded theory are that it is concerned with the development of theory out of data and that the approach is *iterative*

or *recursive*... meaning that data collection and analysis proceed in tandem, repeatedly referring back to each other". I refer to grounded theory to locate myself within a community of researchers who do not limit their analysis with pre-existing hypotheses, leaving them open to the possibility of seeing from the perspective of their participants' lifeworlds. However, grounded theory is itself a broad church. Charmaz (2003) argues that conventional applications are rooted in positivism, resting on an assumed objective external reality, and that later versions from Strauss and Corbin (1997) are best understood as post-positivist. More specifically, I adhere to the phases propounded by Charmaz (1990, p. 1161): "(1) creating and refining the research and data collection questions, (2) raising terms of concepts, (3) asking more conceptual questions on a generic level, (4) making further discoveries and clarifying concepts through writing and rewriting." Grounded theory is understood as a set of "flexible, heuristic strategies rather than as formulaic procedures" (Charmaz, 2003, p. 251). This entails that planning research, data collection, analysis and writing up are contained within a single iterative process, but here they are reported separately for convenience.

While my fieldwork can be understood as an iterative process of analytic sense-making, there was also a more formal period of coding and analysis of text using a computer-aided qualitative analysis programme (NVivo). The textual products of my data collection included full transcripts of interviews; notes from interviews where permission to record was denied, along with shorter notes from recorded interviews; notes from observations of PPF meetings, the CHP meeting, and other events I had attended in Rivermouth; downloaded or scanned versions of official meeting minutes, project reports and action plans from CHP or occasionally Board level. Full transcription was critical in this study, and I did all transcription myself. Kvale (1996, p. 160) discusses transcription as "in itself an interpretative process" and not "a simple clerical task". Attention was paid to pauses and non-verbal utterances, and interviews were transcribed in the local vernacular. This made the process vastly more time-consuming than it could otherwise have been. The choice was initially driven primarily by unfamiliarity with the process of data analysis; uncertain what I would do with the transcripts I resolved simply to type 'everything'. For my interviewees used to articulating their thoughts on the topic of the interview, I can see that a less rigorous approach to transcription would have been adequate in many cases; there is broad consistency of account within the interview. However, for all of the young adult interviewees, and for several of the staff and participant interviews, full transcription is

illuminating. Silences and rambling tangents here are not arbitrary but reflective of uncertainty, either in interviewees' own minds or in the unexpectedness or newness of the question asked. At times these point to questions which jar or fail to connect with interviewees' own understandings of their lives, and this became central to my research findings. This attention to sections of a recorded interview which would often be passed over in more pragmatic transcription is reflected in my use of quotes from young adult interviewees, as discussed below. Editing and cutting ('cleaning up' the quotes) would create an impression of clarity and certainty where this was rarely present. While my transcriptions are thorough I acknowledge that it is impossible for 'everything' to be present: "transcripts are not the rock-bottom data of interviewing research, they are artificial constructions from an oral to a written mode of communication" (Kvale, 1996, p. 163). Nonetheless transcription was a task to which I devoted significant time and attention.

Coding began by working through the data in a single sweep, adding codes in NVivo. This resembles Charmaz's "initial" or "open" coding (Charmaz, 2006, p. 42). At this stage these were mostly descriptive, rather than reflecting "mini-theories" drawn from the literature (Weiss, 1994, p. 193). There was then a period of sorting, where by pulling up all excerpts associated with a specific code I could check for coherence, and split or group codes which seemed distinct or linked. With my tidier codes I then engaged in "focused coding" (Charmaz, 2006, p. 42), going back through data checking for additional excerpts of relevance and rethinking the usefulness or relevance of existing codes. It was at this stage that analysis began to move towards more theoretical accounts. For example, what became my three 'modes' of PPF membership (volunteering, challenging and consultancy) started as rough codes based on descriptions of how members described their roles (work, expertise, change-seeking). Over time, these were refined into theories of what public involvement is and is for, in interaction with existing literature, and including in the process of writing up and communicating the modes at seminars and conferences. Across the project analysis was an iterative process: even at a fairly advanced stage of writing up the thesis I continued to return to coded transcripts as my ideas developed.

Weiss describes this theory development stage of analysis as "inclusive integration" which "knits into a single coherent story the otherwise isolated areas of analysis that

result from local integration” (Weiss, 1994, p. 160). He uses the example of a study of single parenthood, and bringing together findings on relationships with those on practical household management. In this project, the knitting together was primarily of the institutional functioning of public involvement and my young adult interviewees’ personal accounts of their health and health service use. In truth this integration is at best partial. From the earliest stages I have visualised these parts of the project as separate, and the final section of this chapter reflects on the way I which I began to understand this not as a flaw, but as a central finding of my project.

MAKING SENSE OF FINDINGS

Despite aspects of my fieldwork going well, essentially my research design was predicated on assumptions about the meaning, value and significance of the public involvement project, which did not ‘fit’ with either the practice of public involvement or with how my young adults experienced the local health services. The impossibility of asking my young adult interviewees straightforward questions about public involvement mechanisms required me to think further about the application of interpretive policy analysis in this context. With the central question of ‘how does (this) policy mean?’ (Yanow, 1996) and an apparent answer of ‘here, it doesn’t’, I was left confronting the possibility of a failed project. I became preoccupied with ‘the gap’ at the centre of my project; policy-makers and do-ers said that this policy mattered to everyone, this subset of the public not only didn’t know of it but had little to say when it was explained to them. The solution developed out of the insights of Dorothy E. Smith’s account of standpoint research in feminist sociology. This started as an attempt to reconcile her identity as a woman and a mother with her identity as an academic researcher, but has since broadened into a much wider ‘sociology for people’, and has elaborated a notion of standpoint as methodological device.

“It opens up research from a position in people’s lives, from within people’s actual experience, aiming to explore what lies beyond the scope of an ordinary knowledge of the everyday into the social relations that extend beyond us and catch us up in organisation and determination that we cannot see from where we are.” (D. E. Smith, 2005, p. 24)

This helped me to understand “ordinary people” (R. Rose, 1989) – in this case young adults – as a starting point for research, rather than starting within the policy discourse of public involvement. This also resonated with other interpretive research such as Soss’s study of benefit claimants in the USA, in which he explains his ‘hunch’ that “students of political participation needed to pay more attention to the ‘everyday’ claims people make on governments as they try to solve important problems in their own lives” (Soss, 2006, p. 127). In order to take these everyday processes seriously, I had to put to one side my own standpoint within the policy discourse, which essentially, drawing on Hirschman, understands participation as an alternative to marketised and inequitable health services. Spurred on by one telling quote in a pilot interview (“*That [taking part] would just seem like a really strange thing for me to do*”) and an exhortation from my supervisors (“ask them what they *do do!*”) I tried to develop a standpoint in my interviewees’ lives.

This resonates with Li’s (2007b, p. 3) eloquent description of doing research on ‘improvement’ projects in Indonesia, where she describes rooting herself in the daily dynamics of rural life “to make improvement strange, the better to explore its peculiarities and their effects”. Li goes on to describe how her familiarity with the world of international development projects in Indonesia (as with my own experience working on ‘participation’ projects) renders processes “so banal to me ... that they would escape attention”. The gap between “my research describing the dynamics of rural life...and the world of projects, which [staff] inhabit” becomes a productive predicament in which Li searches for “a bridge ... what ways of thinking, what practices and assumptions are required to translate messy conjunctures ... into linear narratives” (Li, 2007b, p. 4). Instead of seeing my interviewees as disengaged or apathetic young adults, I began to attend to the everyday processes of their health. In so doing I engaged in what Berger (1988) describes as “alternation”: “[sociologists] learn how to take on the ways of being in the world that are characteristic of the groups they study. In doing this they learn that their own taken-for-granted-reality, including their most deeply held beliefs, are but one set of beliefs among many” (Pickering, 1992, p. 301). This realisation involved recognising my deep-seated commitment to an ill-defined idea of participation.

Drawing these two projects into one is, therefore, a political statement about the need to attend to everyday experiences within studies of policy and public administration, not

merely as background, but as central concern. This statement resonates with Mol's (2006) demand that health care research should attend less to 'proving' the goodness of treatments and more to 'improving' how they are experienced. However, this research is not, and has never been intended as participatory. I have been involved with participatory research in other contexts and am committed to many of its tenets, but I find the almost evangelical commitment of some authors to be naïve. Shdaimah, Stahl, and Schram (2009, p. 257) argue that research projects which affect to be bottom-up "remain top-down when they are studies of subordinated groups as *subjects* rather than *authors or collaborators*". For them, participatory action research is the only acceptable bottom-up approach except in cases such as "hate groups, people who exploit others, or those who actively abuse power" (Shdaimah, et al., 2009, p. 257). I disagree. In this research project, the exact constellation of topic and perspectives which I constructed is a product of my situated interests and experiences (I do not claim 'scholarly detachment'). The young adults who I interviewed would not have chosen to express views on this topic without my (non-participatory) intervention, and there is much to learn from their lack of interest *and* from their expressed views. Their silences are of interest not as evidence of repressive silencing but because "they are speaking in their not speaking" (Mazzei, 2003, p. 356). An iterative oscillation between policy perspectives (as identified in academic literature, in policy documents, and in local actors' accounts) and 'everyday' service user experiences is a productive approach to research which requires the adoption of a perspective slightly removed from both. To concede the definition of critical research topics solely to 'participants' entails the neglect of unexciting topics worthy of study, and risks falling into the participatory chimera which I discuss more fully in chapter 7.

WRITING UP AND PRESENTATION OF DATA

As suggested above in my account of grounded theory, the process of writing was very much integrated into analysis and sense-making. Invaluable feedback at an early conference presentation at the ECPR Joint Sessions in Lisbon 2009 helped me to make the step from the puzzlement of piloting to the active reshaping of my project. Likewise, two presentations at the Interpreting Democratic Governance conference at De Montfort University in 2010 reassured me that my first steps into writing an interpretive account of public involvement were worthwhile. Writing developed and clarified my ideas in an

iterative process, and I mostly wrote with transcripts and NVivo files open on my laptop next to me.

It is also worth, at this point, touching briefly on how I write up and present data. I have done minimal cleaning up of transcripts, and have retained local vernacular where it is present in the recording. This is intimately connected with questions of class. While I acknowledge the risk that this encourages or allows the reader to “disregard or disparage” (Weiss, 1994, p. 193) the contributions of these identifiably working class interviewees, I feel that unilaterally translating them into another form of English would be disrespectful. As well as locating my interviewees in class and locality, identifiable ‘youth’ patterns of speech (including frequent use of ‘like’) have been reported faithfully. These decisions are likely influenced by the fact that this type of speech is familiar and comprehensible for me, and I hope that they do not prove too much of an obstacle for readers. I acknowledge the criticism that “Letting readers ‘hear’ participant voices and presenting their ‘exact words’ as if they are transparent is a move that fails to consider how as researchers we are always already shaping those ‘exact words’” (Jackson & Mazzei, 2009, p. 2). Remaining committed to interviewing as method, these are simply questions of doing one’s best with awareness of the inherent risks.

In the process of redrafting I have become aware that I am prone to quoting more often, and at more length, than is necessary. While this has been tempered in chapter 4 and 5, my chapter on young adults remains data-heavy. This relates to my point above; uncertainty and unfamiliarity about these subjects is, in itself, a finding of the research. As well as issues of quantity, the selection of quotes is a difficult process, and in earlier drafts it is easy to discern excessive quoting from interviewees whom I found particularly articulate or entertaining (as Kvale (1996, p. 280) puts it, selecting the “best quote”). Accordingly, I have tried to ensure a more even selection of quotes from different interviewees. For each chapter I checked how many quotes from each interviewee were included. This issue is much more prominent in chapters 4 and 6. In chapter 5, interviews with the PPF members were mostly of a similar length and stuck closely to the schedule, largely because they were a group with considerable shared experience. In chapter 4, the disproportionate quoting of Jennifer and Richard in particular reflects the fact that public involvement was central to their daily activities, while for others it was known but on the periphery. In chapter 6, the selection of quotes

is most difficult given the significant variation in how much interviewees had, or were willing, to say. It is also the only chapter in which I do not offer a typology of the differences between my interviewees, and I do not wish this to suggest that this was a group with uniform experiences. Quotes which are included reflect wider trends in the interview data, except where they are clearly noted to be an exceptional view. Quotes from some interviewees are more frequent where they expressed succinctly views which other interviewees expressed in fragments across the interview. It is hoped that this does not create a misleading impression of fluency and strongly expressed views.

CONCLUSION

This chapter has offered a full account of the way in which the research reported in this thesis came about, from initial conceptualisation and planning, through a year of fieldwork, sense-making and analysis, to written product. Questions of quality in interpretive research remain contentious as “the desire for legitimacy in an academic world that is still tied to positivism keeps interpretive researchers questing for a recipe or map that will legitimise their efforts” (Angen, 2000, p. 379). The need for and choice of distinctive criteria to assess the quality of qualitative research is hotly contested (Bryman, 2004, pp. 272-278), but I feel that the debate itself is informative. For example, Cresswell (1998) offers eight criteria (prolonged engagement, triangulation, peer review, negative case analysis, clarifying researcher bias, member checks, thick description and external audits) and argues that any project should meet at least two of these. I disagree with the epistemological basis of several of these. For example a process of triangulation (“labelled after the technique in surveying that allows accurate convergence on a point using measurements from three different angles” (Angen, 2000, p. 384)) makes little sense when I do not strive for a singular ‘truth’ to be confirmed by multiple methods. Despite such qualms I understand the attraction of such straightforward checklists, and still feel somewhat reassured that my prolonged engagement in the field and use of multiple methods mean the project would likely pass Cresswell’s (1998) test.

Rather than debate the precise selection of criteria, Seale (1999) argues that methodological discussions should allow a community of researchers to share and discuss accounts of their decisions and practices. Angen likewise asserts “the term

validation rather than validity is used deliberately to emphasise the way in which a judgement of the trustworthiness or goodness of a piece of research is a continuous process occurring within a community of researchers” (Angen, 2000, p. 387). I believe that a candid account of the research process contributes to this process. Instead of merely a cursory statement of validity, trustworthiness or any of the other plethora of available criteria, “acceptance of the researcher’s case can then partly depend on the capacity of the researcher to expose to a critical readership the judgements and methodological decisions made in the course of a research study” (Seale, 1999, p. 472). I aim to offer a frank account of the actual conduct of this project, including its evolution in response to ‘surprises’ in the field, while remaining closely focused on a constant topic: “Researchers must show how they have done justice to the complexity of their chosen topic by bringing into play all the various, present and historical, intersubjective understandings of it” (Angen, 2000, p. 390). In subsequent chapters I endeavour to retain awareness of the way in which I have, along with my interviewees, produced the particular account offered here, and in chapters 7 and 8 I reflect further on my research design.

4. ORGANISATIONAL PERSPECTIVES

INTRODUCTION

In chapter 2 I reviewed existing literature on public involvement in health, identifying and critiquing the way in which the mainstream approach, dominated by health services research, has understood involvement. In her critique of 'floating sociology', Dorothy E. Smith (2001, p. 165) argues that particular styles of academic writing create "A universe of discursive objects ... in which people, their doings, and time and the local disappear". Specifically, nominalisation, whereby verb forms are converted into nouns ('to involve' or 'to be involved' becomes 'involvement') eliminates "the textual presence of what is done by people" (D. E. Smith, 2001, p. 166). In the next two chapters I aim to denaturalise involvement by putting people and their 'doings' back in to this account of public involvement policy and practice. This chapter presents findings on the local practices of involvement within Rivermouth, firstly describing the assemblage of actors, and then drawing on staff accounts of their roles to suggest three different types of activity which dominated. I offer, if not a total picture of public involvement (indeed given the instability of the term I doubt whether this exists), organisational perspectives on what are seen as the main avenues of public involvement generally, and youth engagement specifically.

THE LOCAL ASSEMBLAGE OF PUBLIC INVOLVEMENT

My initial research plan included a 'mapping' exercise of public involvement (note the nominalisation) in Rivermouth. In the field this proved problematic in two ways. Firstly, an authoritative 'map' required me to ascribe fixed positions where none seemed evident. Secondly, the production of a single map involved adjudicating between alternative understandings of involvement in an uncomfortable way. This chapter begins by introducing the response to this puzzle; the analytic device of assemblage,

which offers a way to present the component parts of public involvement in Rivermouth without constructing a map or organisational chart. I then move on from what Wagenaar (2007, p. 31) describes as the 'hardware' of participatory projects to the 'software'; "the various informal routines, joint understandings, patterns of communication, and practical judgements that have emerged". I present public involvement practice as an uncertain terrain, requiring more than simply the implementation of a policy agenda, and then move on to explore three different approaches to operating within this field.

In aiming not merely to deal with, but to foreground the complexity of public involvement practices I found, I have turned to the burgeoning literature on the analytic potential of 'assemblage': "a conjunctural and evolving ensemble-like formation, which results from the intersection of various ideas and institutional practices" (Sharma, 2008, p. 2). Sassen (2006) attributes this term to translations of the work of Deleuze and Guattari (1988), which locates it within a body of theoretical work that operates at a high level of abstraction. However, she, along with others, chooses a simpler route: "I use the concept assemblage in its most descriptive sense ... I simply want the dictionary definition." (Sassen, 2006, p. 6). Newman and Clarke find it "a valuable concept: it points precisely to the work of enrolling ideas, images, agents and organisations, devices and technologies into something that is presented as coherent, integrated and logical" (Newman & Clarke, 2009, p. 180). One particularly thorough empirical application is the work of Li (2007a, 2007b), who applies assemblage to the field of community forest management. Her definition speaks to my understanding of the operation of public involvement in Rivermouth

"Its elements include things ... socially situated subjects ... objectives ... and an array of knowledges, discourses, institutions, laws and regulatory regimes ... Although the configurations vary greatly, as do the interests served, community forest management qualifies as 'an' assemblage by the consistency with which the set of elements I have just mentioned are drawn together, and by the resonance of the label itself. Like public education or family planning, the label flags an identifiable terrain of action and debate." (Li, 2007a, p. 266)

There are a number of reasons why 'assemblage' is a useful way to conceptualise public involvement practice in Rivermouth, and they are also the reasons why a 'map' would be inappropriate. Firstly, it allows me to recognise the discursive instability and heterogeneous meanings of both the policies which advocate public involvement and the practice which results on the ground. When applied to policy implementation, it allows a bottom-up approach which embraces and explores complexity, rather than demanding that I construct a fixed representation of the links between organisations and actors, with each neatly represented in a single box. Secondly, moving away from understanding policy and practice as two separate happenings (cause and effect or independent and dependent variable) I see assemblage as a process which incorporates both. Thirdly, in the same way as actor-network theory, assemblage allows us to incorporate 'non-human things' (documents, organisations, technologies) as well as people. This is valuable in a terrain where action plans, annual reports and groups such as the PPF seemed to exert influence independent of their authors or members, respectively. Finally, assemblage is a more inclusive device than a map. Li's (2007a, p. 266) "identifiable terrain of action and debate" removes the requirement to apply some external criteria for inclusion: in the field, I often felt that the descriptor 'public involvement' was the only thing connecting the various phenomena to which I was pointed. Events, committees or projects constituted public involvement not because of some common purpose or characteristic, but because actors within the organisation described them as such.

COMPONENTS OF THE ASSEMBLAGE

Several aspects of my use of assemblage incorporate some of the insights of actor network theory (Law, 2003b; Law & Hassard, 1999) without whole-heartedly embracing the approach. Cordella and Shaikh (2006) argue that actor network theory is not a constructivist approach (because it offers an alternative approach to understanding reality) but that interpretive researchers often use it as a lens within constructivist projects; they conclude that ANT is "amenable" to this use, but that its full potential is not exploited. I find ANT opens up new possibilities and perspectives in a useful way (as one critic put it "all this is great fun, but..." (Lenoir, 1999)) and I build on its insights for two aspects of my understanding of assemblage. However, I find its tendencies towards ontological realism and epistemological positivism, as identified by

others (Whittle & Spicer, 2008), clash with my own constructivist and interpretive commitments when taken as a whole approach.

The two aspects of ANT which I integrate into assemblage both concern how we understand actors. Firstly, I work with a looser understanding of ‘actors’ than that implicitly employed by Li (as the author who makes the most explicit attempt to unpick the concept of assemblage). In her analysis of community forest management in Sulawesi, Li (2007a, pp. 267-268) offers a “rough map of the parties” to the assemblage including forestry departments, conservationists, and “forest villagers, real and imagined”. The throwaway “real and imagined” hints at the possibility that these categories of actor are themselves social constructions, perhaps even examples of heterogeneous assemblages, not coherent entities. As Law argues, both organisations and institutions “are more or less precariously patterned roles played by people, machines, texts and buildings, all of which may offer resistance” (Law, 2003b, p. 4).

Law’s advocacy of the inclusion of non-human agents is another point of distinction between approaches based on actor network theory and Li’s map of assemblage, which specifies only (collections of) humans. In Rivermouth, I argue that non-human entities (such as the database on which public involvement activities were to be recorded) had effects within the assemblage independent of their human authors or users. Thus in this section, instead of listing the parties to the assemblage, I identify its ‘components’, including organisations, people, documents, projects, and ‘things’. Even this terminology risks ascribing solidity to fragile, shifting entities, but I would argue that it is a necessary step in ‘having something to say’ about public involvement beyond a cursory statement of ‘messiness’ (see for example Law, 2003a). The existence of non-human agents is controversial (H. M. Collins & Yearley, 1992; Cordella & Shaikh, 2006) but my purposes (justifying the inclusion of non-human components in the analytic frame) are modest enough not to demand answers to some of the profound questions raised by these debates. As Rose and Jones (2005, p. 27) put it “humans and machines can both be understood to demonstrate agency, in the sense of performing actions that have consequences, but the character of that agency should not be understood as equivalent”.

While organisations and staff members are reasonably familiar categories of actor, their use in this context requires some more elucidation. The organisations listed above were undoubtedly “precariously patterned” (Law, 2003b). While protected from some of the pace of structural reform in the English NHS, the Scottish NHS has nonetheless been subject to repeated organisational restructuring, indicated by the left-over branding of now defunct organisations on signs in the Rivermouth administrative headquarters. ‘The Board’ and ‘the CHP’ were the key local structures, but it is important not to overstate their solidity. In particular, the CHP was a somewhat nebulous body. Its public face was a highly formalised committee which had regular meetings in public. The extent to which the CHP had autonomy from the Board was not very clear to the outside eye. Jennifer, the member of staff responsible for PFPI within the CHP, described her role in terms of a series of nested organisations:

Jennifer: My role is really to, any strategy development that comes from the Scottish Government, through the Board for PFPI, and anything that comes there, it's how we implement that locally within the CHP.

Accordingly, although the CHP is the case study unit of analysis, it could be difficult to distinguish CHP activity from that at Board level, and this will be reflected in the analysis that follows.

The remaining three categories of component may require additional description. Firstly, documents. While analysis of language within documents is one fruitful avenue for research (Needham, 2009; Stone, 2002), Freeman (2006, p. 52) has also argued for analysis of documents as “material objects or tools, part of the essential technology of politics and government”. It is in this sense that I consider the documents which were referred to or reached for during interviews and meetings. In Hajer and Laws’ (2008, p. 264) terms, language “create[s] an image of the world that is acted upon and ... constitutes that world at the same time.” Plans and reports did not merely report public involvement, but demonstrated and at times constituted its existence. Secondly, projects were a crucial component of PFPI practice in Rivermouth. These were generally suggested by organisations, carried out by members of staff, and reported through documents (as well as being recorded within the Involving People Database). Finally, the category of ‘thing’ is included to enable consideration of the Involving People Database as an artefact of public involvement in Rivermouth.

The urge to produce a visual representation of these components – drawing together the parts into a whole – is stymied by the contingency of both component and assemblage. Instead, I offer the following list of components, before going on to describe their interaction in the following sections.

Organisations: the CHP committee; NHS Board; Public Partnership Forum; other ‘public involvement groups’ (e.g. the disability network); voluntary sector groups.

People: the CHP PFPI lead; Scottish Health Council Local Officers; Board Equality & Diversity Lead; health improvement staff; local authority participation staff.

Documents: Government white papers; National Standards for Community Engagement and the Participation Standard; Board public involvement stock-take; Board annual PFPI Self-assessment; PPF annual reports and evaluations; Board PFPI action plan; PPF Working Agreement.

Projects: Local Authority Youth Engagement Project; service change consultations; outreach projects for specific service user groups.

‘Things’: Involving People database.

UNCERTAIN TERRAIN

Utilising the concept of assemblage allows us to acknowledge that there was no single fixed organisational view of public involvement work within Rivermouth. Strategic governmental documents such as *Better Health, Better Care*, although mandating action, did not offer day-to-day operational guidance on what public involvement should look like.

Jennifer: There is a lot of work, in the relationship with the Scottish Government saying what we should be doing, but then there isn't a lot of support then. They say what we should be doing, but then it's how do we, I mean we try to embed it in the service but until that happens you really need a lot of support.

Interviewees described Government documents being dealt with mostly at Board level, with the CHP being concerned merely with “*how we implement that locally within the*

CHP" (Jennifer). Accordingly there was significant discretion at operational level about the means of involvement, and a time lag whereby the mutuality agenda of *Better Health Better Care* was only beginning to have an impact. Local actors dealt with the sedimented layers of policy, including a stream of new guidance and frameworks from the centre, and integrated it into their existing practice.

The 'embedding' approach to PFPI – "*it is integral to all we do*" – had created a terrain crowded with actors, projects and documents. William, the Scottish Health Council's local officer, showed me an organisational chart he had produced entitled 'Mapping exercise – public involvement groups'. This identified 57 such groups across the NHS Board, and 8 within Rivermouth CHP. As well as these 8 groups, several of the Board level groups (for example the Disabilities Group) were active at CHP level. Staff described PFPI happening in and through existing organisational structures, more often supplementing than reforming previous practice. The multiple representations of involvement which appeared in these different parts of the system made it difficult for public involvement to have a coherent public face, and complicated the role of the PPF.

Existing literature emphasises the extent to which policy rarely drives change unless it incorporates 'must dos', especially statutory 'must dos' (W. Anderson, et al., 2002, p. 11). The statutorily mandated parts of the assemblage were the Public Partnership Forum, and the roles of the Scottish Health Council's local office. This created something of a puzzle where these structures became out of kilter with dominant organisational approaches. Jennifer described seeing PFPI as about essentially incremental changes ("*sometimes it's just the smallest thing*") and about changing mindsets ("*making people think about what they're doing*"). This is in tune with the Board's PFPI Action Plan, which described PFPI as an integral part of all organisational activities ("*PFPI is not a separate set of activities*"). However, both the PPF and the Scottish Health Council's local work were, self-evidently, separate activities from the usual business of the NHS.

The multiplicity of actors within the assemblage could be a resource: the PPF Reference Group would sometimes refer queries or tasks on to other actors. However, the crowded terrain could also prompt confusion and competition between different groups. With its statutory legitimacy, some understood the PPF to be the main avenue of PFPI; others

saw it as merely one among many. (This resonates with accounts of the demise of Community Health Councils where they became one among many bodies claiming to represent the public (Pickard, 1997)). The PPF was the obvious anchor for public involvement within the CHP (having no other purpose for existence), but few interviewees, other than its members and administrators, were familiar with its role. Terminology was unstable, with Linda, the equalities lead, talking about 'the PFPI' and 'the PPF' interchangeably, and the chair of the PPF's Reference Group becoming confused during our interview:

Chair: Oh gosh I always forget these names, I forget whether we're the Reference Group or whether the larger group is called the reference group.

One specific example of uncertainty around public involvement was that of service changes; specifically the closure of buildings. This is one of the most enduringly controversial issues in the Scottish NHS, where some of the agenda on public involvement has been justified by unpopular closures⁶. There is a nationally-defined process for service changes considered 'major' (Chief Executive NHS Scotland, 2010); however, when 'minor' changes were proposed it was unclear whether the PPF should be a first port of call for staff members to help advise on the consultation, or should be part of the consultation. In both the cases that arose during my fieldwork, the Scottish Health Council local officer advised the CHP on appropriate consultation (contacting existing patients of each surgery with a questionnaire), and the decision was also referred to the PPF, more as an update than a request for opinion. In other issues the PPF would be asked to advise on how consultation should take place. The uncertainty of the group's status more often led to a lack of scrutiny of proposals – on the basis that they would be critiqued elsewhere – than to repeated consideration by each actor.

As well as the number of actors, their shifting roles further complicated the assemblage. The role of SHC local officer had evolved into one closely integrated into the Board and he sat on most of the relevant committees.

⁶ Secretary of State for Health and Wellbeing, Nicola Sturgeon, justified the policy of direct elections to Health Boards as "ensuring that boards will no longer be able to ride roughshod over community opinion, as has happened in the past."

<http://www.scotland.gov.uk/News/Releases/2009/03/12171601>

William: I said, you know what, I would really like to go to your Public Partnership Forum Reference Groups, em, all the time. What do you think? So they went back to the chair who said that'll be fine so I now sit on, it's called in attendance, because I can't participate in developing things and then evaluate them.

This situation illustrates the potential tension within the SHC's role between support and assessment. A national review into the SHC's role during the period of my fieldwork, brought a shift in organisational mission toward support (Scottish Councils Foundation & McCormick-McDowell, 2008), but in practice William appeared to have been downplaying his assessment function for some time:

William: I think initially when it was set up people perceived the Scottish Health Council as the police... And I think that now they're recognising that, 'no they're here to give support'. They do, eh, the self-assessment. But all that means is, they write their own, 'cause we used to write it but they write their own, and we do a little paragraph at the end, like signing off your accounts if you like.

The Board's PFPI Action Plan – self-proclaimed a “living document” – acknowledged the uncertainty and change within this area of work: “the full extent of the required PFPI activity and resources are unknown at present”.

STAFF RESPONSES

Paying attention to the (discretionary) activities of front line workers has been understood as part of policy analysis at least since Lipsky's (1980) seminal work on 'street level bureaucrats'. More recently, as the interpretive turn has complicated notions of “how policy means” (Yanow, 1996), Lipsky's ideas have come to have renewed relevance beyond the narrower field of policy implementation studies. Interpretive policy analysis encourages us to understand the degree to which policy is created in the actions of staff and citizens, as well as by governments and Health Boards. In Rivermouth, I identified three different groups of staff members engaged in quite distinct activities around public involvement. Firstly, a small group of administrative staff at senior level whose tasks I characterise as 'stabilising' understandings of Patient Focus and Public Involvement. Secondly, members of staff actively engaged in 'extending' public involvement, by reaching beyond the mainstream activities of stabilisers and linking with other areas of activity. Finally, I discuss the 'translation'

work of staff working within the local authority youth teams or the NHS health improvement team who operated as a conduit between the unruly voice of 'ordinary' young service users and the rationalistic governance of the CHP. Translation work was to some extent a sub-category of the two broader approaches to involvement. While my research sought out young people-specific involvement activities, which I focus on in this discussion of translation work, reports and plans demonstrated that similar projects existed for other groups who were seen as marginalised.

STABILISING

One response to the uncertainties of public involvement involved documenting and mapping the activity which took place within Rivermouth. The practices which I characterise as stabilising were predominantly carried out by administrative staff within the CHP. This section describes two closely-related stabilising practices: mapping activity and the use of documents. While all of the individuals tasked with 'doing' public involvement expressed commitment to its goals, they also described the very practical, administrative ways in which it was accomplished in their work. The technical-administrative emphasis of public involvement was reflected in its physical locations. Jennifer, the Rivermouth PFPI 'lead', was based in an office in the out-of-town CHP administrative headquarters. Similarly, the Scottish Health Council's local office was on a hospital site in central Rivermouth, but in a separate building, open to the public only by appointment. The tasks accomplished – mostly by individuals working alone – at desks in these buildings were integral to how public involvement existed as part of the CHP, and yet they rarely appear in analyses focused on the more unpredictable public spaces of participation.

The complexity of the PFPI landscape, and the resulting potential for instability, did concern several interviewees. At Board level, perceived duplication of activity had led to the dissolution of one committee of staff members, and its replacement by a committee of Public Partnership Forum chairs from each CHP. This was in response to a Scottish Health Council report which advised that there was overlap and a lack of clarity in the number of groups acting on it. Likewise, the creation of the Involving People database, justified by William as necessary because "*there's a lot going on*" but "*people were not reporting*" can similarly be understood both as an attempt to 'capture' or pin down, and

to demonstrate to outsiders, the public involvement activity happening within the CHP. The database was created by Jennifer, and seen as so successful that it was adopted by the other CHPs. Jennifer described the database both supporting the sharing of 'good practice' and the reporting of PFPI activity to CHP, Board and SHC.

Service Area	Your CHP/Ward/Department
Date(s) and Duration(s) of Activity	Time span of your activity
Aim of Activity	Why you were undertaking this activity – eg, to raise awareness, to review quality, to seek views, to make a decision etc
Tick (✓) all boxes that apply	
Passive	Was the activity designed to just give patient information?
Active	Were you responding to a situation or seeking views?
Interactive	Were people involved in making a decision?
Participative	Were you building capacity to enable further contribution in the future?
How were people supported to participate?	How did you involve people who are house-bound, or people who have dementia or did you provide transport for people who would otherwise have been unable to attend?
What was involved?	What methods did you use – questionnaires, focus group, interviews, open day, display boards, etc.
Who were involved?	Who else did you work with and how did you involve them?
What did it achieve?	What were the results?
What helped the process?	What helped you achieve what you set out to achieve eg, carers were keen to participate, the volunteer service you work with sent out letters to potential participants.
What hindered the process?	What delayed the process eg, difficulty in securing funding for stamps, the original plan to conduct focus groups was discarded due to lack of participants.
How were changes fed back to those involved?	How did you feedback the results of the engagement and any subsequent changes to the agencies, participants, staff involved.
Resource Implications	What did it cost? Staff time, money, envelopes, etc.
Further details are available from:	Enter your name, address and contact number so that others can contact you for further information.

Figure 2: excerpt from template for Rivermouth Involving People database

Figure 2 shows the template for information required by the database. It breaks down the activity into neat, accessible steps, including asking the staff member to clarify whether their activity offered passive, active, interactive or participative involvement. The implied pinnacle of involvement – “participative involvement” – is described as “building capacity to enable further contribution in the future”. It is pertinent that this classification is separate from “what did it achieve?” (a question subtly different to its explanatory note “what were the results?”). While fulfilling reporting requirements, the database also performs internal functions, shaping and delimiting the possibilities for PFPI through examples of ‘what works’. Having to answer the questions “how were people supported to participate?” and “how were changes fed back to those involved?” encourages staff members to give thought to these issues, and makes it clear that they are necessary steps for good practice.

Another way in which the meaning of public involvement was stabilised was through the system of written reports and ‘evaluations’: within the PPF; from the PPF to the CHP committee; from the CHP committee to the Board; and from the Board to the Scottish Health Council. Requesting or offering a ‘report’ was listed in minutes as a frequent outcome of meetings at all levels; this was where the idea of a ‘stocktake’ of activity, and William’s mapping exercise, had come from. Reports primarily documented activity and satisfaction. In the case of presentations from staff or attendance by PPF members at other events and meetings, Jennifer instituted a system of written evaluation. All present PPF members and the staff presenter would fill in a short evaluation form. These evaluations were collated into quarterly reports for the PPF, which included how satisfied all concerned were with the experience. The PPF’s annual report to the CHP enumerated activities which members understood as contributing to their impact – attending meetings, having staff attend their meetings – and demonstrated less focus on engaging a range of members of the public. PPF priorities were more about demonstrating influence (with the annual report identifying two ‘key challenges’: “Seek evidence to show the PPF has made a difference. Seek evidence to show the PPF influenced the CHP and its services.”).

Reports created substance for organisational processes, and a paper trail to evidence activity – but as operational documents, rarely engaged with the wider purposes of public involvement. In the sociology of translation, particular attention is paid to

documents which act as ‘boundary objects’; artefacts which bridge two different ‘worlds’ or realms of action. Rivermouth CHP documents, both in their production and in their use, were required to bridge the world of administrators and managers with that of health professionals, often while satisfying the policy-makers who would monitor their action. They also had to be acceptable in the public realm. This is a complicated role to play:

“Because more than one world or set of concerns is using and making the representation, it has to satisfy more than one set of concerns ... Representations, or inscriptions, contain at every stage the traces of multiple viewpoints, translations and incomplete battles.” (Star & Griesemer, 1989, pp. 412-413)

Documents were often reached for, or pointed to, as a means of stabilising understandings of PFPI within the assemblage. William identified dealing with a stream of documents from national and Board level as a key part of his work. When asked about his day-to-day work he responded by fetching a large, well-organised ring binder of action plans, development plans and work plans. While Cavaghan (2010) analyses one organisational unit’s use of documents to stabilise understandings of ‘gender mainstreaming’ within the EU Commission, I would argue that in Rivermouth, PFPI documents often functioned with little reference to their content, avoiding any statements which might define or specify purposes or methods of PFPI. Rather, the existence of ‘a’ document (a plan, a report, or an evaluation) was the stabilising force, which acted to cover over disagreements about meaning.

EXTENDING

In the Scottish Health Council’s local officer William, and the (newly created role of) NHS equalities lead Linda, I found two people who had an alternative vision of public involvement to that embedded into everyday life in the CHP. I characterise this as extending because it stemmed from a basic dissatisfaction with the mainstream approach, and a recognition that formal meetings were failing to reach much of the population.

William: Now, one of the difficulties is that if you’re having meetings during the day, then you’re going to get, a predominance of retired people. Because people who are out working, or Mums with families, [throws up hands] where do they have the time?

Linda: *Because the PFPI I think are really just getting to grips with [engaging and consulting]. They're still into big events. A lot. But what we need to do is get away from big events and have focus groups. We need to go to where people are already meeting.*

Both Linda and William acknowledged that the diversity of the public being reached was a concern about the PPF. However, the statutory existence of the PPF meant that its legitimacy endured where a less formal project might not have (Linda: *The Government pushes for them to do it. That is their role, is to be able to prove that they're out there involving the communities*).

While some concern was expressed about helping the PPF to engage with a broader section of the public (the CHP arranged a 'development day' for the PPF with a range of aims including "ensure the right foundations are in place to help the Public Partnership Forum to broaden the range of people they include") renewing public involvement more often looked outside of the statutory mechanisms. The result was a very different understanding of how PFPI should look. Linda recognised the statutory legitimacy of the PPF but struggled to reconcile this with other areas of her work where different notions of representation prevailed (Linda: *it's very easy to say yes we've got groups, and we've got reference groups and we've got web pages, but who sits on these groups?*) Outside of the formal public involvement which took place in an orderly, bureaucratic fashion through the PPF, William and Linda both undertook ad hoc 'outreach' work with local groups and advocated moving away from the events-centred approach they associated with the PPF:

William: *As opposed to the scattershot approach to the public is the rifle shot approach that says, let's pick 'em off ... So I'm convinced that this is the way for us to go, you know, get out there. Not to say, oh, come along, but for us to go and meet them there, where they meet, when they meet, so if it's a weekend, if it's an evening, whatever.*

This involved operating at the edge of their administrative job descriptions, and in William's case created something of a tension in his day-to-day workload, which thus included both public-facing outreach work with marginalised groups as a representative of the NHS (*"I'm going away to see the Chinese elderly people because there's an issue about diabetes"*), and responding to requests from NHS staff as an external source (*"it's something we've been asked to look at"*).

Extending projects looked different in that they were tailored to 'pick off' particular groups of the population, rather than being designed to answer a pre-defined question. Events were tailored to fit in with existing plans, so were less like a formal meeting:

Linda: You know if I had a meeting for the deaf society or people, the people who are deaf and actually use British Sign Language, I reckon I'd get none, to come along. But if I go along there on a Tuesday night, like they are really pleased to see me, and talk about issues that they're having about accessing our services.

However the tailoring (William: *What they wanted was somebody from public health to come along and talk about swine flu. But it's not the big overall arching policies they're interested in. It's about how, what affects their health, at this given time*) meant that extending events were less suited to feeding into existing decision-making processes. As contact didn't take place within the structure of an existing consultation, there would rarely be a resulting course of action to justify. William said that information gained at these events would contribute to his decisions about signing off the Board's PFPI self-assessment. As a member of Board staff, Linda was able to advocate for changes more directly, without waiting for a review or consultation to feed back through. She used the example of changing hospital rules to allow deaf patients to use mobile phones on ward to send text messages.

Outreach work started by identifying groups who were available and/or under-represented. This approach was, in its way, as technical as much of the stabilisation work. Instead of the all-affected principle of democratic theory, Linda was concerned to engage with 'equalities groups' as defined by the NHS Scotland equality schemes for disability, gender and race. In one case, Linda described working with community groups from outside the area in order to develop resources for patients in area. Here achieving a successful outcome, via accessing 'community' knowledge, was defined with no reference to the existing public within Rivermouth. Linda and William exercised significant discretion in identifying these groups, but Linda said she wanted better patient monitoring to allow more rigorous selection of under-represented groups. 'The Chinese elderly' or 'The Polish Association' were both seen as under-represented, but these 'target populations' also had the advantage of being easily accessible through existing associations. Other target groups – such as British Sign Language Users – were identified as under-represented by staff and external support was brought in to engage with them. This was how the 'translation' work accomplished with young people by

health improvement staff and youth workers was initiated. While the next section will reflect more on that process, the way in which 'hard-to-reach' populations were identified by NHS staff and existing engagement efforts co-opted into public involvement belonged firmly in the camp of the extenders.

TRANSLATING

Staff accounts pointed to the 'engagement' of young people within the CHP as an additional facet of activity not satisfied through the PPF, and the CHP committee had requested that additional work be done with this group. Health improvement staff and local authority youth workers were seen as the key individuals conducting such work. Interviewees talked about four projects in particular. The first was a network of Youth Forums facilitated by youth work staff, described by staff as flexible, ad hoc structures led by young people's own interests. Another project, the Debating Project, was planned by health improvement staff as a series of training workshops for young people followed by a debate with local service providers. The Youth Perspectives Project consisted of one-off focus groups with existing groups of vulnerable young people: young carers; young people excluded from mainstream education; young people living within an area of disadvantage; young people not in education, employment or training; teenage parents; and young people at risk of drug addiction. Finally, health improvement staff ran a Drop-in Service across a range of youth clubs in the area. Staff tailored the drop-in in response to feedback and requests from young people, and accordingly the service broadened out with sexual health issues to cover all "teen issues". This section characterises the engagement work of these staff as translation between service use (and tales thereof) and the governance of the CHP.

Firstly, views were gathered. Projects mostly reached younger, school-age people. In some cases this was intentional, as for the Youth Perspectives Project, which targeted 14-18 year olds because "*it is during these middle teenage years that important stages of development occur*" (project report) but also for practicality. In others, namely Drop-in Service and the Debating Project, organisers had hoped to reach older age groups. In common with the emerging approach for mainstream Rivermouth public involvement, staff tended to work through existing groups rather than trying to recruit from the population at large. This was the case with the Drop-in Service but also Youth Forums,

which worked by formalising groups of young people who were already meeting socially.

Pat: You know, we call it a Youth Forum and sometimes staff get a bit hung up on that and think that a Forum is a definite thing but that might be a campaigning group, it might be a pressure group, it might be a skate park needed or something and so that's what we call these Forums, em so it's shorthand really for where these people come together.

Staff described a number of advantages to this approach; it was quicker and meant that the expertise of existing support workers was available. However, working with or through existing groups also had its tensions, including imposing external (NHS) priorities on to groups who exist for other purposes, such as respite for young carers.

All interviewees preferred working with small groups of familiar young people. Frontline members of staff, working in the Drop-in Service and in Youth Forums, described knowing groups of young people well and working with them repeatedly across different projects:

Karen: A lot of them knew my face, so it it was quite easy. That's, recruitment was not a problem.

This trust enabled Karen to draw together groups in response to requests from other agencies, sometimes at short notice.

Karen: So, I got an email, and they had like a week to make [a consultation event]. So, em, [named group of young people], yet again, you know because I had this lot's email addresses fired it off to them 'who can attend?'... They were there, at the railway station, at 7 o'clock on a Saturday morning, knowing they should still have been wrapped up in their beds but keen as mustard to go along.

Karen describes the pragmatic way – last minute requests, convenient channels of communication – in which groups of 'usual suspects' emerge in youth engagement. Sometimes these young people went on to stand for election to the Scottish Youth Parliament, and this led to being in considerable demand to sit on various NHS and local authority committees. Where this trust – or at least familiarity – was absent, it was seen as a major obstacle to engagement (*Karen: it would have to be sort of cold-calling just as they're walking in and out type of thing, trying to get them, and if you're not a known face, that's sometimes really difficult.*).

Views were often gathered through projects with a developmental focus familiar from community development approaches. The Debating Project is a good example; young people worked through a 'pack' with health improvement staff before preparing for the meeting with senior staff.

Karen: Em, and it basically gets them just to, initially gets them to look at, you know, what they think are issues for them. And then it gets them to think well if that's an issue, why is it an issue?

This was described as a respectful process, working with expressed views and exploring them further. Nonetheless Donna's comment that one of the Youth Perspectives Project focus groups was "*maybe not as controlled, or as tight as I would have liked it to have been*" hints at the disciplining force of these ongoing relationships, which helped young people to articulate views on services within the confines of the existing system. Staff described trying to strike a balance between giving young people control and helping them to express views effectively. Pat described how one youth forum had come up with a proposal to produce a booklet for distribution at a cost of £9 per copy, at which point staff had intervened to come up with a more affordable alternative.

The other side of translation was using known information about young people's views, 'needs' and experiences to influence the local management of services. Staff described a number of facets of this influence: frontline staff and youth representatives sitting on committees; bringing together groups of young people with local politicians or service managers; and information-sharing through reports and presentations. The role of frontline staff in advocating for young people's perspectives has been highlighted, and indeed defended, in other literature. Macpherson's (2008) study of socially excluded young people highlighted the potential of specialist youth workers representing their clients' views in partnership committees, and the difficulties encountered by such staff: "In stepping outside the adult world and aligning themselves with young people, advocates confuse their peers" (Macpherson, 2008, p. 374). Karen talked about this in less dramatic terms as becoming 'a pest' (*we're always telling other people how they should treat young people*). Health improvement staff described their own role on committees as a key mechanism of influence, heavily informed by their own frontline and consultative work. Donna described consultation work as assurance for her that committees she sat on were working on the right issues.

Other projects worked by bringing young people into direct engagement with service providers and politicians. Mark described workshop type events as the best way to influence service providers, but both he and Karen emphasised the challenges of creating a dialogue with suspicion on both sides:

Mark: And there's key councillors who have a general interest in young people and will come along and they're very good with young people. There's others that are interested in hearing about young people but won't engage with them they'll just sort of sit back.

Karen: They just felt they would be palmed off. They thought [service providers] would have time to think about it and come up with a smarmy answer that was... They really wanted to get reactions and get them on the spot. They really liked it. The service providers really didn't like being put on the spot. So it was one of those things, em...

Engagement staff operated as a conduit, trusted to some extent both by young people and the decision makers.

An additional mechanism of influence came from the reports which were produced for each project. These were seen as a key output of the projects by interviewees, and I came away from each interview with a pile of reports. For the Youth Perspective Project, a 50-page report had been produced. The main sections of the report included an analysis of themes from focus groups, using short quotes to exemplify each theme. Many quotes are in local youth vernacular, and several are provocative (for example, “get rid of old grannies” “kill the junkies”). A warning about this is added to the section ‘research objectives and methods’:

“Comments have, in virtually all cases, been taken at face value. It is inevitable, however, that some comments would have been made to try to shock the facilitator, or to show off to friends. The analysis has not attempted to differentiate these comments and uses virtually all of the material gathered. Readers should note that direct quotations are presented within this document which some people may consider offensive.”

This can be seen as an example of the challenges facing ‘engagers’ in mediating between the informally-expressed, unorganised speech of young adults and the formal committee structures which wait to hear their ‘voice’. The final two sections use no direct quotes and transform the fragmented themes of earlier sections into ‘key messages’ and

recommendations. To exemplify disconnects within this process, I attempted to trace each of the six bullet-pointed recommendations back through the key messages into the themes section. For example:

Recommendation: "Building on good practice established within the Board area, sustain, support and further develop the Family Health Project. This project comprises of Family Health Midwives and Nursery Nurses providing enhanced support to vulnerable groups, including teenage parents."

Key message: "Midwives were regarded as a key support during pregnancy."

Theme: "With the exception of lack of sleep, and to some extent, anxiety arising from concerns about their children, there were no health issues raised. Generally, midwives were viewed very positively, although doctors were not regarded particularly well."

This example is chosen because it is more specific and thus traceable than others (for example: "*Continue to engage and involve young people in planning and developing responsive health improvement initiatives*"). However, it demonstrates the process of taking messy statements from focus group participants, ironing out some of the inconsistencies ("*Generally, midwives were viewed very positively*" becomes "*regarded as a key support*") and fitting them into the known decision-making context of the CHP ("*regarded as a key support*" becomes a recommendation to develop a project that does not appear to have been mentioned by any participant). Here, frontline staff used their own knowledge of 'what works' in supporting teenage mothers to translate uncertain, vague statements into clear-cut recommendations with clear actions for the organisation. Within this document, the fault lines in the assemblage of 'public involvement' – the absence of shared meaning which is comprehensible for both 'ordinary' young adults and the committees which seek their views – become visible.

One reason for this process of translation was that the views elicited from young people did not fit neatly into the questions asked or decisions being made within the Rivermouth CHP. Sometimes this was because views crossed into the terrain of other public services.

Donna: Things about their environment, things maybe about that there's nothing to do in the evenings, and all these types of things that the NHS maybe not directly would have an

influence over but certainly sitting on strategic groups and partnership groups, we could work with the partners to maybe address.

However, it also related to the broad, societal nature of challenges identified. For the health improvement staff, this was an intrinsic challenge of the broad understanding of health with which they worked:

Donna: You're sitting with young people, 'what do you mean health? Oh I eat pizza and I do this' so it was about spending a wee bit time to say 'well health is much more than that, it's what makes you happy, what makes you sad, how do you feel about this'... I knew what I wanted to get, but as soon as young people hear health, they think pizza, chips, that type of stuff.

Here, Donna describes the process of moving beyond instinctive 'gut' reactions to questions about health, to the broader wellbeing focus of much health improvement ("I knew what I wanted to get"). Having transformed young people's focus on their own actions into a 'health improvement' focus on environmental and societal contributions, Donna was left with some remarkably broad-sweep conclusions. This necessitated an approach of picking small achievable actions out of the broad scope of consultation:

Donna: We've produced this report ... and obviously there's, there are recommendations that come from it that are fairly broad, em, but what is a result of it is that I now have a work plan where I'm going to try to progress some of this work forward, em, and hopefully, drive some improvements where maybe found I don't know we found one or two things that maybe could be looked at or work around a specific topic.

Sometimes, by contrast, recommendations seemed troublesome because they sounded trivial when placed within the context of local health services management. Talking about GP practices and the recommendations of *Walk the Talk*, a national project, Karen explained:

Karen: They're just, it's always like, em, like you go in and it'll be golf magazines and like women's weekly or something, you know... One of the Walk the Talk recommendations is to sort of make them a bit more young people friendly.

In Rivermouth, health improvement staff operated as a two-way conduit for young people's views. They advocated for young people's priorities at the level of CHP and community planning, but they also reflected understanding of what is and isn't

acceptable or achievable back to the spaces in which they coached and shaped young adults' views. I understand this not as a malign or repressive act but as a pragmatic response to the gap between the way young adults spontaneously discuss their health, and the way in which health service management decisions are made. This reflects the distinction Yanow (1996, p. xiii) makes between organisational processes as "rational-technical", compared with more mundane, 'messy' lived experiences. Public involvement creates demand for the experiences of service users to be brought into these 'rational' and technical settings. Accordingly, practitioners such as Donna, Karen and Mark find themselves in the position of needing to enact a process of translation: "a sense of doing something other or more than merely telling, of communicative and perhaps creative exchanges rather than dissemination" (Freeman, 2009, p. 441).

CONCLUSION

This chapter describes the transformation of PFPI from the national policy discussed in chapter 1, into an unevenly embedded part of administrative life in Rivermouth CHP. Using the analytic device of assemblage, it attempts to describe the various components of the day-to-day practice of PFPI. Within this there are numerous tensions: between a formalised, separate process of quasi-representative voice; an outreach and diversity-focussed model of direct or participatory voice; and patient focus, a set of activities which rarely engage with voice at all. While the separation of patient focus and public involvement in Scottish policy is often seen as a progressive step, their continued intertwining allows staff to concentrate on the least disruptive or contentious parts of the agenda around making services 'better' through technical means.

I argue that these uncertainties and gaps within organisational accounts of PFPI place pressure on documents and on staff members as boundary objects and mediators of the purposes and meaning of public involvement. We can recognise that, although the assemblage of public involvement can generally proceed with minimal consideration of the absence of shared understanding, there are occurrences which stretch it too far. If one such disruption is the provocative, light-hearted statement of a young person in a focus group ("kill the junkies"), then Donna and her research report need to improvise to bridge this fault line, to allow this 'voice' to be heard without destabilising the

assemblage by forcing questions as to the acceptability of the 'public' which is to be 'involved'.

5. PPF MEMBERS' PERSPECTIVES

INTRODUCTION

As a statutory requirement for the Community Health Partnership, the Public Partnership Forum (PPF) occupied a key role in the local assemblage of public involvement in Rivermouth. As highlighted in chapter 1, the policy agenda around public involvement has shifted even in the relatively short period since the creation of PPFs. While PPFs remain in place in almost all areas, in policy documents they have changed from being the “main mechanism” (Scottish Executive, 2004, p. 4) of involvement to “one of many different ways” of “listening and responding” (Scottish Health Council, 2010, p. 16). In comparison with the amount of literature on similar organisations such as Community Health Councils (Ham, 1980; Klein & Lewis, 1976; Pickard, 1997), or Public and Patient Involvement Forums (Baggott, 2005; Warwick, 2006), Public Partnership Forums have not been well-researched. The most comprehensive study is a piece of Government-commissioned research by a private consultancy which accordingly seeks to advise as much as to understand (FMR Research, 2008). Anton, McKee, Harrison, and Farrar (2007) mention their creation only in passing, and most generalist accounts of Scottish health policy since devolution omit them entirely (Keating, 2010; Tannahill, 2005).

While chapter 4 described the PPF as only one component of the broader organisational assemblage of involvement in Rivermouth, it remains one of the most tangible, ‘purpose-built’ facets of involvement. This chapter therefore presents findings from a more focused exploration of the PPF. In doing so, I concentrate on the ‘Reference Group’, a committee which was often described by staff and members as ‘the’ PPF, despite the existence of a larger database of other members. Despite the inclusion of both ‘partnership’ and ‘forum’ in its title, the PPF was predominantly a traditional committee of between nine and eleven members of the public (varying during my fieldwork) who met on a monthly or bi-monthly basis. Acknowledging that “it is in the micro-politics of institutional engagement, rather than through officially espoused views or strategies, that the public is constituted as actors” (M. Barnes, Newman, Knops, & Sullivan, 2003, p. 396), this chapter explores how public involvement was enacted in Rivermouth PPF, based on observation and interviews with members of the group. This level of access

allowed me to become a familiar presence, with some knowledge of group dynamics, and to use my observations to inform and direct interviews. Clinging (metaphorically) to Arnstein's (1969) ladder, I entered the field in search of the politics of public involvement. Spending a year observing decorous meetings in formal conference rooms, and talking informally to members of the PPF in coffee breaks and car parks, I was surprised at the lack of challenge or contest in the day-to-day life of the group. Interviews, shaped by this 'puzzle', gave me the opportunity to explore participants' views on the matter.

This type of organisation – elite-initiated, unelected, including representatives of voluntary organisations, the public and the state – is now a recognisable feature of public sector governance across the UK and internationally.

"Today many – and probably most – new forms of citizen activism do not occur outside the political system in civil society. Rather, they take shape inside this system in various governance networks and partnerships between private, public and voluntary organisations." (Bang, 2005, p. 160)

The nature of participation in such "invited spaces" (Cornwall & Gaventa, 2000) poses a number of challenges to conventional political science literature on participation (Qvortrup, 2007). Civic engagement, certainly since Putnam's (2000) defence of community and the activities which build it, sits uneasily between altruistic voluntarism, and the self-interested or group-interested activism of political participation. In a literature which has often started from the assumed benefits of *any* civic engagement, 'volunteerism' and 'activism' or 'campaigning' are often elided. For example, Harre justifies her joint consideration of them as follows: "Both types involve making a contribution to the community that is not financially lucrative for participants ... While these kinds of engagement may be considered distinct, in practice, individuals and organisations are often involved in both" (Harre, 2007, p. 713). While it may be reasonable to elide these categories in studies of civic-engagement-for-civic-engagement's-sake, a more critical approach requires some distinction. Traditional definitions of political participation concentrate on two dimensions of difference (Conge, 1988; Qvortrup, 2007). First, and conventionally, voluntarism and activism can be distinguished as being elite or citizen-initiated (Qvortrup, 2007). A small group of local citizens mobilising themselves to protest about a hospital closure seems straightforwardly bottom-up, while a volunteer responding to an advert and fulfilling assigned

tasks is invited. However, there are grey areas even within these examples. Autonomy or discretion in defining actual tasks might be more pronounced in some voluntaristic endeavours than in very structured activist projects. Secondly, we can distinguish reformist or static (conservative) activity (Qvortrup, 2007). As in Harre's (2007, p. 713) distinction of activism as seeking to change social structures and volunteerism directly helping those in need, we can distinguish actions that are supportive of existing structures from those which seek to change them. Again, this distinction is useful in a heuristic sense, rather than representing a clear-cut empirical difference.

The chapter will begin with a scene-setting section, describing the day-to-day operation of the PPF and introducing its members, with reference to debates about the 'ordinariness' of civic participants (Learmonth, et al., 2009; Martin, 2008a). The second section outlines a typology of 'modes' of PPF membership; the public roles available or performed within this invited space. Finally, I discuss the management of failures and contradictions within the PPF as one everyday practice of assemblage (Li, 2007a), emphasising the manner in which the PPF's nebulous mission aids its resilience.

SETTING THE SCENE

In Rivermouth, the PPF 'manual' describes the aim of the Forum as "supporting the open discussion of issues relating to health and health services in Rivermouth". The PPF had been up and running since 2005, and consisted of a large database of interested parties (groups and individuals who had signed up to receive questionnaires, event invitations etc) and then a smaller 'Reference Group' which would have physical meetings on a regular basis. The interested party option was available to individuals, but was primarily intended to represent local community and voluntary groups:

"Communication undertaken by the PPF will be tailored to ensure maximum inclusion of all sectors of the community, making use of and supporting existing mechanisms developed for community planning and community involvement." (PPF Manual)

According to the only national evaluation of Public Partnership Forums, this is a fairly common model (FMR Research, 2008). In 2009 there were 84 groups and 39 individuals in the wider PPF, including the ten individual members of the Reference Group. The

wider database existed primarily as a mailing list, which was tailored by the inclusion of a list of tick boxes on the 'membership' form. These offered the options of receiving information, commenting on proposals and/or contributing to working groups and committees. It also listed 30 areas of healthcare (e.g. diabetes, GP services) in which members could indicate an interest. As a mailing list, the wider PPF did not offer opportunities for members of the database to communicate with each other. A 2008 Scottish Health Council survey of all PPF members in the Board area listed ten written comments on membership from Rivermouth members. These demonstrated the wider PPF's tenuous existence with most responses either unclear about what they had joined ("I would like more information"); requesting more accessible public meetings; or stating that it is 'early days'. Accordingly, my own research focussed on the Reference Group.

REFERENCE GROUP MEETINGS

I contacted the Reference Group through Jennifer. When I asked if meetings of the Reference Group were held in public Jennifer paused and replied "well nobody's ever asked", but made it clear that the decision was in the hands of members of the group. Members made it clear in interviews that the central function of the PPF Reference Group was its meetings. These physical meetings were, in themselves, a key manifestation of public involvement within Rivermouth. Understanding the nature of this collective endeavour is, accordingly, necessary to understand public involvement in Rivermouth. The Reference Group was composed of between nine and eleven members of the public during my period of fieldwork, plus a representative each from the Scottish Health Council and the Local Authority. The group appointed a Chair on a bi-annual basis, in an informal, consensual fashion.

Chair⁷: The initial Chair, I wasn't quite ready, I thought let's see how this is going to work out first, so I, somebody else being the Chair and then I said I'd be Vice-Chair. Now [Vice-Chair] is my Vice-Chair and he'll step up so we'll have a rolling... so we keep changing it and get fresh ideas and things.

⁷ To protect the anonymity of PPF members quotes which identify the Chair and Vice-Chair will be left anonymous.

Almost all of the communication outside of meetings was by email or post, with phone calls between Jennifer, the Chair and Vice-Chair. The PPF members did not know each other outside of the PPF, except two who were members of the local Disability Network.

Overall, although meeting participants' needs, the PPF seemed to me to lack a public face, and to be a nebulous entity. Meetings moved between different locations – a community centre, a town hall, and a meeting room at one of the hospitals – as Jennifer tried to find a venue which was accessible geographically as well as for those group members with disabilities. Although in part a deliberate strategy to move around the geographical area of the CHP, this contributed to my sense as an observer that the PPF lacked a physical presence. Jennifer's office was the nerve centre of the PPF but this was a small, cluttered administrator's office in an out-of-town hospital building, not a public-facing space. The lack of a PPF website was also notable, as was the repeated confusion from both members and other staff about the name of the group. Despite reasonably exhaustive working agreements, 'manuals' for members and regular evaluations, the lack of a clearly defined role or 'home' (whether physical or virtual) made it difficult for any interested outsiders to access and understand the PPF without making formal contact with Jennifer.

Meetings were held monthly when I started observing the group, but this moved to bi-monthly as part of ongoing discussions about the best way to run things. Thomas talked about the trade-offs involved:

Thomas: We tried to reduce the burden, making the meetings every two months. Well if it's every two months then you're probably going to have to have a full two hour meeting, of the agenda if you like. Em which disappointed me because it was me that promoted at least half of the meeting should be towards development of the group.

Attendance varied, with the local authority representative absent from all but one meeting. We always sat round a table, with Jennifer sitting on one side of the Chair and an administrator taking minutes. Drawing on literature which emphasises staff manipulation of public involvement mechanisms (Harrison & Mort, 1998), I was initially suspicious of this arrangement. The PPF Chair however, described it as a welcome and supportive arrangement:

Chair: *I always like Jennifer sitting on my right-hand side, I don't know if you noticed, because she's better sitting there so she can say you've gone too fast, slow down or, you know, eh, or I can say help me on this one!*

Each of us had a nameplate, which was handed to us after we had chosen our seat, and two laminated cards – “I need some help” and “I want to speak” – to hold up if necessary. In practice this system was not used often or consistently. As one of the group members who suffered from a hearing impairment complained to me:

Robert: *They're not using them properly. Em, because somebody will start speaking... and it takes me a while to see who is speaking, and by the time I find them, I've missed their first sentence or so, and don't really know what they're talking about. And then they'll stop and somebody else will start and so I miss half of what's being said.*

While trying to accommodate the varied abilities and challenges of the Reference Group's members, the pressure to get through the agenda tended to make this difficult. The meeting agendas were often quite full. However, the vast majority of items were for information rather than decision. Each item would have the initials of the relevant member next to it, and these were almost always those of the Chair, Vice-Chair or Jennifer, updating other members. Some items came along with a paper to discuss, but many were verbal updates on meetings attended. Every meeting began with a formal nomination and seconding of the previous meeting's minutes. Overall the PPF's meetings seemed replete with structure, even ritual, and lacking in substantive decisions.

I understand my observation of meetings as a revealing process in two ways. Firstly, and as predicted, I developed an understanding of 'what goes on' within meetings as the primary activity of the PPF. I was able to observe the processes which would make their way into meeting minutes and evaluation reports in sterile terms. Secondly, and relatedly, I became more aware of the 'underlying imagery' with which I had approached the PPF, drawn from my previous research, from literature, and from my broader lifeworld. Many of the observations described in this chapter are those where these two pictures jarred or conflicted. From the earliest point of arranging to observe the PPF, I was perplexed by the lack of attention to the public outwith the Forum, or to the PPF's public face. Early observations left me wondering why there was so little

substantive content to meetings, but also why I had expected there to be more. I carried these 'puzzles' forward as orienting devices for interviews with members.

MEMBERS

Concerns in Rivermouth about representativeness in public involvement (as discussed in chapter 4) are not a localised problem. The spectre of 'the usual suspects' has haunted the policy and practice of public involvement mechanisms in the UK. As far back as 1975, Community Health Councils were criticised by NHS staff for being "unrepresentative" (Ham, 1980), and this complaint was also directed at their successor organisations, Public and Patient Involvement Forums (House of Commons - Health Committee, 2007). Despite the sophistication of our theoretical accounts of representation (Pitkin, 1967) academic literature on public involvement has largely failed to offer a convincing response to these criticisms: Crawford, Rutter, and Threlwall (2003, p. 46) find "statements about representativeness are very common in the literature but the meaning of the term is rarely considered". Learmonth et al (2009) discuss the 'catch 22' of populating involvement mechanisms with individuals who are simultaneously seen as 'ordinary' and have the time, confidence and skill-set to be, as policy demands, 'effective' on committees. As discussed in chapter 4, in Rivermouth, concerns about diversity were present, but vague. In the PPF's manual it stated simply that "It is important that the PPF is truly representative".

Where formal processes of authorisation (via election) are absent, concerns about representation tend to manifest in demands for 'ordinary' participants and criticism of 'the usual suspects'. It is possible to distinguish two dimensions of representativeness which tend to recur in discussion and debate about public involvement. Both can be seen as a response to the unfamiliarity of notions of representation where a formal process of authorisation via election is absent. Firstly, there is a demographic question, which Martin describes as "descriptive-statistical" (Martin, 2008a). This essentially demands that representatives resemble those they represent in demographic characteristics (Pitkin, 1967). A second, which is often hinted at but rarely elaborated on in academic literature, is a simple concept of 'newness' to civic activities; essentially one cannot be both 'ordinary' and one of 'the usual suspects'. This connects to concerns about the informality or absence of processes of authorisation and accountability

(Pitkin, 1967) in what are often self-selected mechanisms. The absence of descriptive representation is, Warren argues, a major flaw in citizen participation initiatives, which should be resolved by methods such as random selection of participants (Warren, 2009a).

(How) were Rivermouth PPF members representative? In terms of descriptive-statistical representation, even given the constraint of a sample of 11 people and a population of 40,000, the members were not descriptively representative. The gender split on the PPF was uneven; nine men and two women. All were white. All were over 45. Seven PPF members were retired due to age or ill-health. Three out of ten still had jobs, and one of these members left the PPF during my study, citing time commitments as his reason. Two had disabilities and most had some ongoing health problems. In terms of social class, Rivermouth is not an affluent area, with 17% of the population income deprived (compared to 14% Scottish average) (Scottish Public Health Observatory, 2008). This was probably under-reflected in the PPF membership. (Retired) working class members had worked in construction, cleaning, and social care. Middle class members had been school-teachers, a senior nurse, in the military and self-employed small businessmen. Accordingly, many different demographic groups were under-represented. However, as Pitkin (1967) argues, it is impossible to produce a meaningful synecdoche of the whole population, thereby necessitating some form of sampling with associated imperfections. Furthermore, even were it possible to produce a perfect sample, simply 'being like' the population in demographic characteristics is only a partial account of what political representation means (Pitkin, 1967).

An alternative dimension of ordinariness is about authorisation and accountability (Pitkin, 1967). In this unelected "invited space" (Gaventa, 2006), this entails a focus on the way the PPF recruited its members. The PPF was four years old, and most of its members had been directly recruited by the CHP, by sending letters to known voluntary health and social care groups in the area, or by approaching former members of the disbanded Community Health Council. Other members had heard about the PPF from friends. Several were experienced committee members, who had often 'graduated' from a local major Board-wide consultation exercise a decade earlier. James had a particularly convoluted route on to the PPF, including personal invitations. He was, in many ways, the archetypal 'usual suspect'.

James: *I stayed with the Health Council, and ended up as Chair of the Health Council... And then Scottish Health Council took all the local ones over, eh, so I was sort of kicking around for about six months or so and then the Chair of the Health Board then phoned me up and said would you be interested in coming round to the Community Health Partnership when it was first formed? So I said yes, and I didn't realise in what capacity I was going on for the time being because the PPF hadn't been formed then. But eventually I was public representative on the CHP that was my role. Then the CHP came along, the PPF came along and eh I became a member of that, founding member of that.*

Often members could not quite remember at which point they had heard about or joined the PPF; they were well-connected in their community and it could have been from a number of different contacts or mailing lists.

ES: *Okay em and how did you hear about the forum in the first place?*

Michael: *Em, good question! Eh it's one of these things that sort of creeps up on you in a sense, cause I was in, I joined the em, heart support group side of the CHP. And I think the option to become involved in this came through that ... Em since, but it was through that I think just a sort of widening membership of other committees and things.*

This widening membership in a range of health-related participatory activities, some overlapping between support for other patients and influencing services, is fairly characteristic of the PPF members.

For both Mary and Margaret, progression into the voluntary activity which brought them to the PPF was rooted in their social worlds, not in their own health issues. Mary described the process by which she had fallen into first helping out, then co-ordinating a small, informal lunch club for women recovering from strokes.

Mary: *Well, my friend J ... after she had her first stroke and I wasn't working she was going on about em, the group was gonnae fold because of the volunteer they had, the escort they had, had been caught stealing in old people's houses ... I just said to her well look J you say to the powers that be there and just, I'll, if you ca'ae get anybody else I'll come along and dae it.*

After taking over Mary began receiving "the bumph" (letters and information) from the Community Health Partnership, including repeated letters asking for volunteers for the PPF.

Mary: *I kept getting this one about, for the CHP, and I says oh I'm fed up o' this, it was like every week, what are youse going' to dae about it? "Oh you just answer it Mary and eh, we'll see." I says right. So I got an answer back they were wanting' tae interview me about going' on the committee. Now I'm no' a committee person. Right? ... So that's how I then got up on the committee.*

ES: *And what, what do you mean you're not a committee person? What sort of thing?*

Mary: *Well, the thing is, well the... [the previous organiser of the club] decided what they done and when they done it, but since she's died, they have to decide, and then I make it work. And that's, me. There's nae point sitting' blethering if you're nae going' tae do the job. With anything like that.*

Mary had fallen into civic engagement through more informal volunteering in her community, and described initial feelings of irritation and suspicion at requests for her to enter the world of 'committee people'. Margaret, more straightforwardly, had heard about the PPF from a friend and enquired directly. Even more than for the male members, Mary and Margaret described their entry into the PPF as located within social networks.

As 'new' entrants to the world of committees, Mary and Margaret were not 'usual suspects' like James or William, but by a peculiar logic their membership of the PPF transformed them instantly into usual suspects. The fear is that a small group of 'elite' participants – or "expert citizens" (Bang, 2005) – are over-represented on many committees within the governance of a local area (as Mary put it "*a' these men seem tae dae nothing but go to this committee, that committee, and the next committee*".) Behind this fear lie underspecified parallels with more traditional political activity; PPF membership as the equivalent of giving a small, particular group of the population multiple opportunities to vote in an election. As the next section will argue, this underestimates the extent to which participation within the PPF was conducted with a strong focus on 'the public good' and key members displaying a suspicious attitude towards actors seen as pursuing self or group interest. These two dimensions of 'ordinariness' – an expectation of descriptive representation of the population and of a mode of recruitment that reaches hitherto disengaged individuals – become analytic 'dead ends' as we query further into the demographic characteristics or past experience of PPF members. This links with a literature which has tried to problematise the notion of an out-there 'public' awaiting representation:

“This assumes a singular and reflective voice – rather than a heteroglossic, and potentially conflicted, view of potential or emergent publics. Ideas of ‘summoning’ or ‘convening’ publics point to the political work of imagining potential ‘we’s’ and findings ways of inviting or recruiting them” (Newman & Clarke, 2009, p. 182)

This approach directs our attention to the PPF as a process of summoning the Rivermouth public. In the next section we will further explore the different approaches members took.

A TYPOLOGY OF INVOLVEMENT MODES

As time went on I began to see in meetings, and especially to hear in interviews, more of the nuances of PPF activity. While I saw little of the overtly challenging behaviour I had expected, there was no single shared understanding of what public involvement was, and no stable, officially mandated ‘right way’ to do it. In an attempt to make sense of what I saw, and how members explained it to me, I constructed three ideal-type ‘modes’ of PPF membership (see table 5). As chapter 2 outlined, this is not an area of literature lacking in typologies. The original typologies from Arnstein (1969), Feingold (1977) and Charles & Di Maio (1993) focussed on the organisational perspective; assessing the degree to which citizens were in control. In recognition of the overwhelming lack of interest much of the population has for actively controlling public services, more recent typologies ask instead what role the public would like to play (Litva, et al., 2009; Thompson, 2007). Litva et al’s (2009) framework involves roles (citizen, consumer, advocate) and types of involvement (overseeing, informing). In my case, by grounding my typology in participants’ own understandings of their everyday practice within the PPF I produce three categories which encompass both role and task. Two of these modes (volunteer and consultant) emerged from discussions with PPF members and from a debate observed in a PPF meeting. The third, challenging, was brought into the research by my assumptions about the nature of public involvement activity. I include it as something of a negative category: its absence enhances the heuristic value of the typology and reveals the significance of the emphasis on non-activist modes.

It is important to state that these modes describe ways of being a PPF member, and not people. Becker (1998, pp. 44-46) argues that creating typologies of actions, rather than

of people, leads sociologists to attend to change and acknowledge the complexity of individual behaviour. This is an important difference between my typology and that offered by Simmons and Birchall (2005, pp. 269-271). There is some instructive overlap between my categories and those they develop – notably in their characterisation of ‘campaigners’, ‘foot soldiers’ and ‘scrutineers’ – but drawing on surveys they build types of participant, and include within their types characteristics such as educational qualifications. I am encouraged by some of the similarities between the modes of participation we identify, but am clear that in Rivermouth PPF these were not fixed categories but available roles between which members could, within the inevitable constraints of the social context, shift. Some PPF members mostly seemed to operate within a particular mode, but most shifted about, and some seemed ‘stuck’ operating in modes which did not correspond with the motivations they described.

Table 5: characteristics of modes of PPF membership

Mode	Offering	Agenda	Frustrations	Model activity
Volunteering	Service	Reactive	Lack of activity	Hand hygiene stall
Consultancy	To advise	Reactive	Lack of respect	Planning a survey
Challenging	To change	Proactive	Lack of change	Questioning a member of staff

VOLUNTEERING

Most of the members described simply joining the PPF in order to be ‘helpful’, often after being flattered by a personal invitation from the staff setting it up. Their motivation was more akin to that of a traditional volunteer than interest representation:

James: *It's eh, going back to the original idea of joining the NHS as a volunteer, you know it sounds terribly grand and grandiose to say this but I'm, as I say when I joined it at the time I was getting benefits for, getting the disability benefit getting this benefit, that benefit, and I thought well I'd like to do something to sort of show that I'm not completely just sitting back and just getting benefits.*

Many members felt they owed a great debt of gratitude to the NHS (Michael: I owe my life to it.) Members also told me they enjoyed the opportunities to learn more about the NHS. For example,

Michael: *I suppose if I'm honest the main thing that got me involved with the Forum would be having a heart attack... Since then I've been kinda anxious to eh well, find out as much as I could about the NHS.*

Mary: *The thing it does dae is gi' you more confidence and mair insight into how things are working. Ken?... And you di'ae lose your temper the same way. You di'ae lose the plot the same cause you've got the, that wee bit extra know-how into how it's been or how come it's happened like that or why they're no' dae'ing it.*

The expressed gratitude and enthusiasm to learn meant that far from needing to repress or co-opt criticism within the PPF, staff sometimes seemed to be trying to summon up a critical attitude. At one discussion on the PPF's manual, Jennifer urged members to be "like the police" when attending committees.

Members had been recruited to the PPF through existing volunteer work in health-related community groups, and the PPF was for many of them an extension of this labour. Echoing other research findings on volunteering (Roberts & Devine, 2004), several talked about enjoying the opportunity to learn and to be part of something. Duty also played a part. Mary, a member whom I rarely observed speaking in formal meetings, had a long history of trade union and political party activism, as well as her voluntary caring work. When I asked her whether she enjoyed the role she replied:

Mary: *Eh, enjoying it's no' the word. It's something that people need to do. That's how I see it. They wouldnae come in and send me the letters to come and interview me, to put me on the committee, if there wasnae somewhere along the line I was going to be able to, thought I maybe could gi' something. Ken? Or get the benefit o' something.*

Mary thus explained PPF membership as part of her duty in the community (to give an as yet unspecified 'something') rather than as part of her activism to change things. She understood that the NHS 'needed' members of the public to be part of the PPF, and her voluntaristic response was to conscientiously attend meetings without an agenda of her own. This attitude to the PPF meant that most members had few preconceived ideas about what the PPF *should* be doing, preferring to await requests for assistance. Donald explained:

Donald: *We often have people in giving talks, well, you'll have seen that for yourself. Eh, and they ask us for comments... And we'll give our comments, and they usually take them on board and they'll come back another time and say how they've got on. Eh, and how the comments that we've made have made a difference or not.*

Donald's description suggests equanimity on the question of influence. It would appear that for him, making a difference (or not) is something of an afterthought. His priority seemed to be simply to help.

Drawing on Arendt's (1998) tripartite division of action, the nature of the help which my interviewees described seemed mostly about 'labour' (i.e. non-instrumental activity), as opposed to 'work' (activity towards some specific production) or 'action' (reflexive interaction). As the "foot soldiers" of the PPF they concentrated on "support functions" rather than the strategic direction of the group (Simmons & Birchall, 2005, p. 270). However given the nature of the PPF support functions were not the leaflet delivery that Simmons and Birchall (2005) cite. Membership was instead about being on the committee, in the room at the meetings, doing the reading, putting one's hand up at the appropriate moment to nominate or second the minutes. These were reactive, even pre-defined tasks which were rooted in presence. That a meeting had happened (that members of the PPF had sat round a table with agenda and note-taker) demonstrated involvement separate from any criteria of influence or initiative. For some members, this could add up to a significant time commitment (in one of the Chair's reports he had represented the PPF at nine events in the previous month, as well as preparing for the regular meeting). While members all told me that they would speak up if they were unhappy about a development (Mary: *"Well, but if there's anything comes up that I'm no' happy about, or I'm no' sure about, I've got the bottle to say."*) this situation very rarely arose and meetings were very consensual. In reaction to the sometimes repetitive

sharing and feeding back of information, members sometimes wished there were more tasks to complete. James told me that in the early days of the PPF

James: It seemed fairly sort of, eh, you know, as if nobody could really give us a reason why we were there ... but eh you know we we're finding ourselves a bit more of a remit now and finding ourselves jobs to do.

At times other requests came to the PPF, such as when volunteers were sought to run a stall in the hospital foyer promoting hand hygiene. As an observer, drawing again on my assumptions about PPF membership as political action, I assumed members would find this a patronising request. While Robert raised this in a later interview as an example of work “anybody could do”, he was in the minority. Three PPF members volunteered enthusiastically, and reported enjoying the event. For Margaret this was a welcome example of ‘actually getting to do something’:

Margaret: You know ... going along for example to the hand hygiene, I felt that had some influence on people, coming in to visit or use the service and things like that, because you could actually demonstrate to them, look this is what we need you to do, here's the reason why, here's how you do it properly.

The welcome potential for influence here was influencing the public at large, and not the organisation. It therefore cohered neatly with a ‘service’ orientation (“directly helping those in need” (Harre, 2007)) and was most prevalent where members identified uncontroversial, straightforward needs. Echoing Roberts and Devine’s (2004) finding that participants often reject the label of activist, members often seemed to find this a more comfortable or appropriate role than one which sought to challenge the NHS. As James put it: “I keep politics out of it”.

CONSULTANCY

My second constructed mode of membership understands the PPF as a group of experts on public consultation (Charles: “a sounding board, so that when people were actually passing information out to the public ... they'd run it past us, the methodology that would do it”.) Several members said they wanted a more project-based role for the PPF, where

issues would be explored in depth rather than being discussed briefly at one meeting. Thomas envisioned a role for the PPF akin to that of a market research consultancy, planning and carrying out small pieces of research on public opinion.

Thomas: As I see it the PPF is, our Reference Group is a mechanism by which the CHP can communicate or, em, to establish the best means of interfacing with the general public so, we're that interface, you know. It's, it's almost like, if you were in a private company you wanted to do some advertising, you want to get your message across, okay, and so you employ a marketing agent or a whatever, a PR type organisation, and, say right I want to go over, this is the message I want to give this is, I'm trying to establish a brand or, you know, a product, or whatever, and he takes it on and does it. That's the way I see the PPF, to the CHP.

The PPF here is envisaged as a conduit for the public's views, which offers its ostensibly neutral expertise, not its opinions. Thomas expressed frustration that staff brought proposals to the PPF for feedback, rather than asking the PPF to lead on doing the work itself. He explained that this wasn't because he was unhappy with the consultations that the CHP ran, or because he felt the PPF wasn't being taken seriously ("we're being kept informed, and we're making our comments, and those comments are valued"). He described wanting a more 'involved' role to become more expert and be more helpful.

Another member, Robert, explicitly used the language of consultancy when discussing his role in the PPF, although his occasionally combative approach in meetings meant that I often saw him as the PPF's main challenging member. He performed highly skilled tasks for the CHP and the Board, such as reviewing building plans for appropriate disability access. Robert expressed irritation when a member of staff came along to one meeting to talk about the Board's Investing in Volunteers award (beginning her presentation with "*You probably don't see yourself as volunteers, but the public involvement you are doing is volunteering.*").

Robert: We're not volunteers. As I said at the last [disability group meeting] it was agreed that I wasn't a volunteer. I was a consultant. Not only because of my knowledge and expertise, but because I wasn't there as an individual. I was there representing another organisation ... All volunteers with the NHS have sort of managers, and people who organise them and what-not. Nobody organises me. Nobody tells me what to do, where to go, when to be there for. We're totally different.

Robert distinguished himself from the volunteers on the basis of his representation of an external group, and his autonomy and independence. Elsewhere, he emphasised his specific skills and knowledge, as in his politely disparaging comment about the hand hygiene stall: *“You know, well anybody, if you’ll excuse me, could do that. It doesn’t have to be someone with my interests or expertise”*.

CHALLENGING

As discussed above, I was surprised in meeting observation that there was little in Rivermouth PPF that seemed to challenge the local NHS organisation. In interviews, members almost never spoke in such adversarial terms. In some cases, members told me about putting aside issues they felt strongly about in order to adopt a ‘helping’ orientation within the PPF. James campaigned for wheelchair users in his spare time, but was adamant (and observation and analysis of minutes support) that he would not raise such issues through the PPF (James: *“You know I would say that’s my fight that I’m fighting, that’s nothing to do with the, the PPF, so that’s never brought up”*). James expected this of other members too, and talked about feeling pleased that ‘tub-thumping’ was not part of the PPF:

James: I’ve hopefully got a good crowd around me at, that understand that there’s a lot of different points of view to be heard at the table, and eh you know so far nobody’s been you know, tub-thumping about their own particular cause. Which to me is very good because as I say although I’m supportive of everybody’s causes, you know, we can’t do, be seen to be honing in on one.

Here partisanship – understood as a prior partiality to a particular group’s perspective, rather than to a political party – was seen as understandable but inappropriate within the PPF.

The two exceptions to this in PPF meetings were when problems were expressed through humour and “anecdote” (Young, 2000). There were occasional moments of challenge, but they rarely made it out of the realm of banter round the table. In one discussion of the delay in renovating a local clinic, Charles asked why the Chief Executive of the Board was getting a pay rise when this project was held up by a lack of funds, suggesting a “generous donation” might be in order. The comment was laughed

off good-humouredly, and when I asked Charles about it later he shrugged and smiled. Anecdotal tales of problems experienced by friends or neighbours arose perhaps once a meeting. However, like jokes about executive pay rises, these were not expanded into a consideration of the 'big picture'. Donald mentioned one such story he had raised with a member of staff during the meeting:

Donald: *Dr X said yes, fair enough, but it is quite common for people who's had brain operations, to have strokes. So I thought well [shrugs], no' much I can say about that! So that's it.*

ES: *Were you happy with the response? Was it, what you were after?*

Donald: [Pause] *Well, I got an explanation. Which is all I could ask for.*

Robert's behaviour was more overtly challenging. He had joined the PPF through his activism in the local disability group, and his personal interest in disability did shape his membership.

Robert: *Em, there have been, in the past wee while, a couple of things that I would have liked to branched out from there and got involved in. But to be honest, I don't have the time, you know. And they weren't, em, [disability] wasn't really involved an awful lot in these particular things.*

Present on his own terms and with his own goals in mind, Robert described being selective in the tasks he would take on, preferring those which furthered his clearly defined aims. Expressing this openly distinguished him from other members, and he could be relied upon to persistently ask difficult questions on the basis of his particular interests. He laughingly described himself as a nuisance, but the small concessions (such as the improvement of hearing loops) which he proactively raised at meetings took many months to show any progress.

MAINTAINING THE PPF: FAILURES AND CONTRADICTIONS

The previous sections have argued that there was considerable distance between different members' understandings of the PPF's role, using the heuristic device of a typology of membership modes to demonstrate the differences. Although disagreement

very rarely surfaced in meetings I observed, in interviews it became clear that members were aware that the PPF was not a unified group with the same understanding of their purpose. James talked about past members who had become fixated on one issue and failed to commit to the reactive, supportive approach he favoured. Thomas expressed frustration that members were not willing to commit the time to become more expert about local health services by sitting on further committees or attending NHS-led 'development' sessions. Mary admitted that she often felt out of her depth compared to very experienced committee members, and William said it was difficult to hold his own. Margaret, politely, complained about the sharing of anecdotes. Robert compared his own knowledge and experience to members who preferred tasks that "anyone could do". Members recognised the lack of consensus of purpose within the group, and the next section will explore the ways in which this dissensus was managed in the everyday life of the PPF. Given the uncertain definitions of public involvement discussed in chapter 2, uncertainties in the everyday practice of public involvement are to be expected. However, the overwhelming lack of challenging understandings of the PPF's role suggests that public involvement in Rivermouth is heavily biased towards the first of these frames.

As described in chapter 1, this coheres with the supportive role that legislation sets out for PPFs (Scottish Executive, 2004). The fact that the PPF rarely constituted a political or challenging presence within Rivermouth resonates with previous literature about the way that "invited spaces" (Gaventa, 2006) can shape what goes on therein (M. Barnes, et al., 2007). New institutional theory directs our attention towards the question of the source of this imbalance: how do members learn to behave? Beyond the very broad descriptors of the PPF manual I was unaware of any 'official' statement of appropriate PPF membership in Rivermouth. No formal training was given to new members, and I saw no evidence in observation nor interviews of more subtle forms of censure from Jennifer. If anything, the opposite is true; new members wanted more direction, and several quizzed me as to what the PPF should be doing. However, members' memories of the (abolished) Community Health Council, as well as similar spaces, shaped emerging practice. Davies, Wetherell and Barnett describe this in the case of the creation of NICE Citizens Council: "although [it] had zero history in itself, the mix of discursive practices which came to constitute it trail behind them convoluted histories" (Davies, et al., 2006, p. 200). In interviews, one of the newest members of the Group mused about the potential for challenge within the group:

Margaret: *But I'm just no' sure that we're absolutely clear in relation to what sort of clout we have! If any! You know? I mean can we go along there and say 'no, this is not on'? You know, here we have this, we have that, and, and this really isnae the way to go. Do we have that, degree of, of clout as I say, or are we just there to go 'oh well that's what's happening. Mm. Well, not too happy about it, we'll see what the public say.*

Margaret's concerns around the PPF's 'clout' highlights the lack of clarity around membership, but also points at the way in which existing modes of behaviour in the PPF shaped new members' understandings of appropriate behaviour. She described her frustration with the current mode of activity and yet was cautious about whether it would be appropriate to move outside this to adopt a more challenging role. Robert simply chose to behave as an activist, repeatedly raising the issues he cared about in a manner which came very close to the 'tub-thumping' of which James disapproved. As Barnes, Newman and Sullivan argue "the interaction of actors will frequently result in the reformulation or adaptation of rules and norms. It may also involve the co-existence of 'old' and 'new' rules over time" (M. Barnes, et al., 2007, p. 61).

Returning to the analytic of assemblage outlined in chapter 4, I understand these differences in the practice of PPF membership as tensions within the local assemblage of public involvement. Li (2007a) outlines six key practices which maintain assemblages, including "managing failures and contradictions". These are managed, rather than resolved, through "fuzziness, adjustment and compromise" (Li, 2007a, p. 279). A good example of this was the revision of terms of reference for the PPF during my fieldwork. This involved the document being posted out to all members, and an item placed on the agenda where members could raise changes they wanted to make. The catalyst for the discussion was the Chair's suggestion that the terms be amended to reflect the fact that the PPF would comment on the substance, as well as the methodology, of consultations brought before them. This distinction was an important one in practice, as for example when a manager brought a proposal for a two-day consultation event on the proposed closure of a ward (with the service being moved into the community). The existing patients and their carers had already been consulted and were apparently satisfied. In this situation the group were consulted as experts on public involvement, and asked for their views on the 'methodology' of the consultation. However, the requirement for an instant response meant there was little they could contribute beyond broadly supporting the idea of a consultation event.

Analytically, this change to the PPF's constitution involved official acknowledgement of the lay volunteer and, potentially, the challenging roles some PPF members preferred to play, instead of the official 'expert' consultant role. However, there was no ranking of roles, or editing of the existing understanding of the PPF. More roles were added, but none were taken away; the PPF's uncertain purpose was simply made 'fuzzier'. My sense that this discussion on the PPF's official identity was talking round the issue at hand brought to mind Barry Barnes' description of the maintenance of organisational identity.

"[H]ierarchies, organisation and institutions ... are not 'external' structures with an independent existence; they are entities which must be continually constituted and reconstituted in the minds of their members... That is perhaps why there is such an obsessive concern, in hierarchies and organisation, with the dissemination of knowledge of how they are constituted, and why mutual learning is constantly reinforced by visible symbols and ritual representations. Without the ongoing process of learning there is nothing to be learned about." (B. Barnes, 1993, p. 215)

Thus the discussion was not merely debating the PPF as an 'out-there' entity, but actually creating it, with the words on paper ('terms of reference') as tangible evidence of its existence. The discussion continued with a number of technical amendments to the terms of reference document, relating to the frequency of meetings and allocation of committee positions. As an observer, this discussion seemed to be avoiding the central question of purpose. However, Thomas persisted in trying to clarify the PPF's role, raising the example of reporting back from other committees, asking whether this was adequate and whether he should be doing more. In the silence that followed, Jennifer, the NHS staff member, tried to outline her vision of a public involvement role which Litva et al (2009) describe as "overseeing", entreating members to "be like the police" in committees, watching out for problems from a patients-eye view. This role divides between two of my ideal type PPF members, requiring both the regular, dogged presence of volunteers and the willingness to hold to account of a 'challenging' mode. It was the closest anyone came during my fieldwork to attempting to state an 'official' role for the PPF.

Another incident which highlights contradictions in the PPF's role had occurred before my fieldwork, but was mentioned in interviews by several members. In response to a

consultation methodology request, PPF members had suggested a series of public meetings, which had then been very poorly attended. James had gone along and was horrified at the level of apathy.

James : There was nobody there when I got there, and then two people turned up, one of whom was an ex-councillor and you know, they'd laid everything on, there was sort of two members of staff there... and me, and two others. And my taxi driver, who has to stay on just to fill the place up a bit. It shows you that the apathy's not just about the PPF it's just generally.

For him this confirmed the essential unwillingness of the public to give up their time. Thomas's perspective was different. For him, the PPF had failed in its expert role, because it had not been given the time for planning necessary for consultancy.

Thomas: It wasn't, detailed, it wasn't dealt with in a detailed way, it was dealt with at a meeting, a presentation, 'what would you think?' Well, you could have meetings in certain areas around. A good suggestion, for what it was worth, didn't work out at all. They got nobody to the meetings so we had to come back and revisit, well how would you look at this again?

Thomas expressed embarrassment about this situation but there appeared, from minutes, to be no re-evaluation of the PPF's ability or willingness to offer technical advice to support consultations.

CONCLUSION

Drawing on members' own descriptions of their membership, I identified at least three potential interpretations of the role and purpose of the PPF. One was about volunteering and service: members sought to fill their time by giving something back, and preferred to do so in a tangible way – for example by being present at a committee meeting. Another was about offering expertise: members had clear ideas about how the NHS should be improved and sought to inform decision-makers. Finally, there were fleeting glimpses of the role I had initially anticipated most members to seek, one based on challenging the organisation, where members try to change the NHS as a structure. The general unwillingness of anyone to impose their own interpretation on the PPF (as either Jennifer, the Chair or indeed the CHP organisation could have done) meant that instead the PPF muddled through, accommodating the ill-defined goal of 'public

involvement' by accumulating an ever broader mission statement. Where the PPF proved unable to fulfil tasks asked of it, members could fall back on alternative understandings of their job, leaving only Thomas worried and vexed on the subject, and looking for ways to avoid a recurrence.

The PPF was in many ways an odd hybrid of two different types of organisation. With its loose, ill-defined criteria for membership and occasionally nebulous feel it resembled a governance network: "a web of relationships between government ... and civil society actors... dispersed, flexible and in some cases transparent modes of agenda-setting, policy-making and implementation" (Klijn & Skelcher, 2007, p. 587). However, in meetings it functioned like a traditional bureaucratic committee. This can be related to the statutory mandate for the existence of a PPF: because it had been mandated to exist before anyone had a clear sense of what it should be or do, it had evolved peculiarly, with a great sense of urgency that things should happen (as in the difficult decisions about the need to meet monthly) and yet an overwhelming lack of consensus on *why*. As an example of elite-initiated civic engagement, those setting up the PPF appeared to have made a genuine attempt to create space for members to define its mode of operation. In a sense there was too much space, and too little direction or purpose. I do not recognise the PPF in either of Barnes, Newman, and Sullivan's (2007, pp. 190-193) "institutions as sites of challenge and opportunity" or "institutions as prisons". Rather, the PPF as institution was overwhelmingly a site for work, a sense of personal usefulness, and (for those members who stayed engaged) enjoyment (Roberts & Devine, 2004). Asking questions about the degree to which it represented citizen control, or whether staff manipulated it as a 'technology of legitimation' assumes that there is an assertive, ready-constituted 'public' available to take control or be repressed. Just as policy-makers may seek to mobilise an imagined responsible, quiescent public, research can project 'activism' on to an imagined public which does not seek citizen control through these mechanisms. Rather, the PPF's presence within the assemblage offered personal advantages to its members while fulfilling the Board's statutory obligations. In the next chapter I turn from this summoned public to the perspectives of a group of individuals for whom this was an unknown and uninteresting world.

6. YOUNG ADULTS' PERSPECTIVES

INTRODUCTION

Previous chapters have highlighted efforts made by the assemblage to engage with the public in general (and young people specifically) in Rivermouth, and the concern expressed about their lack of engagement. While these concerns were to some extent highlighted, or even prompted, by my presence as a researcher with a pre-defined interest in young adults' involvement, youth participation was on the agenda in Rivermouth anyway. While conventional hypotheses of staff manipulation and blocking apply to youth involvement as much as general public involvement, this specific example also encounters a set of debates around youth apathy and alienation from political and civic participation in the broadest sense (Marsh, et al., 2007; Russell, 2007; Sloam, 2007). Therefore, what the Hirschman-influenced literature on exit and voice in the NHS would describe as the 'supply' hypothesis (young people are not involved because involvement mechanisms exclude or fail to include them) is accompanied by a number of potential 'demand' issues:

- Young adults are passive or apathetic
- Young adults are not or should not be interested in services they rarely use
- Young adults are happy with the services they use

These issues are potentially relevant to most citizens, and not just young adults. However they are particularly well-rehearsed when we consider young people specifically.

Young adults – 18-25 year olds sometimes referred to as 'emerging adults' (Arnett, 2004) – are an illuminating group of service users to focus on for two reasons. Firstly, their patterns of service use are distinctive, and pose challenges for conventional models of voice and choice. Furlong and Cartmel (2007) discuss youth and adolescence as a time of peak physical health, following childhood vulnerability to congenital and infectious diseases and before the degenerative diseases which are more common in adulthood.

Youth is, however, a period of different types of risk, with accidental injury, poisoning, self-harm and sexual ill-health the most prevalent health problems (Blum & Nelson-Mmari, 2004). The frequency of self-reported mental health problems among young people has grown significantly (Furlong & Cartmel, 2007). Lightfoot and Sloper (2006) point out that most public and patient involvement activity aimed at young people in the English NHS is about health promotion, not services. Accordingly, in young adults' interactions with the NHS their role is rarely that of a straightforward victim of chance. Their health problems may be seen by professionals or society more widely as consequences of their own (intentional or otherwise) actions, or of health issues which remain stigmatised and ill-diagnosed.

Recent generations of young adults are also frequently understood to be less, or differently politically and civically engaged than other age groups (Furlong & Cartmel, 2007). The gap in electoral turnout rates between the old and the young continues to increase with generations (Russell, 2007, p. 23). However a significant number of scholars argue that political participation has not diminished but changed (Dalton, 2008; Norris, 2002; Pattie, et al., 2004): "Political energies have diversified and flowed through alternative tributaries, rather than simply ebbing away" (Norris, 2002, p. 5). Studies of these alternative tributaries are testing the boundaries of definitions of politics, either by moving away from action towards stated views, or by moving away from a social change orientation to focus on lived experience. Marsh, O'Toole and Jones (2007), drawing on their qualitative study of youth participation in the UK, argue that young people remain articulate and knowledgeable, and that a lack of formal engagement with politics is a response to their limited efficacy. In a similar vein, researchers have looked away from attempts to change structures towards lived politics. Riley, Griffin, and Morey (2010) explore 'neo-tribes' within electronic dance music culture as a "facet of politics". Skelton and Valentine (2003) explore the way in which young D/deaf people use British Sign Language as a (political) act of resistance. The implications of this literature will be more fully discussed in the next chapter, but for now the relevant point is that contemporary young adults do not participate in the same way that older generations did.

This chapter begins by discussing my interviewees' experiences and views on public involvement, politics, and civic participation more generally. I term this section 'researching an absence', in recognition of the fact that these questions, driven by the underlying imagery (Becker, 1998) which I brought to this project as a researcher, probed an area of life which seemed to hold little relevance for most of my interviewees. The next section presents my interviewees' accounts of their everyday experiences with the NHS, characterising these as moments of agency and negotiation. Finally, I draw upon Scott's (1990) concept of resistance, and de Certeau's (1984; de Certeau, Jameson, & Lovitt, 1980) concepts of anti-discipline and everyday creativity, to explore the subtle ways in which my interviewees exerted agency within the NHS.

RESEARCHING ABSENCES: YOUNG ADULTS, FORMAL POLITICS AND PUBLIC INVOLVEMENT

After the experience of interview piloting, I planned interviews from an assumption that young people probably wouldn't know about Public Partnership Forums, or about other consultation opportunities. Instead, using consistent wording, I carefully described the PPF, and asked a single question: "How does that sound to you?" Interviewees mostly felt that the PPF was a good idea, and had a range of views on why.

Rachel: Sometimes, if people dinnae voice their opinions, nothing really changes eh. So if they've got people to help them, and they've got percentages and stuff like that, then things will improve eh. If people willnae speak then things willnae really change eh.

Nicole: Yeah alright I suppose, if they're speaking to people and actually finding out what people want then, I mean rather than people sitting down saying right, we'll do this, we'll do that. Find out what people think, and then, try and put it to use.

While these answers seemed broadly supportive of the idea of public involvement (the existence of opportunities for it), it was largely discussed as an activity to be practised by some other group of people.

Few said they could envisage themselves playing a part in the Forum. The idea of regularly attending meetings on generic topics was described as particularly strange. For example:

Megan: Em, unless folk are like me and then you can't be bothered, doing it. Like I would say I'm fine with filling out questionnaires, but for like meetings and things like that, I probably wouldn't be that great because, like everybody's days off are going to be different and finding times to meet and stuff... And I don't know if some people would think, oh actually I'd rather do something else. Like, I don't know, I know I should care about it but [laughs] I just, it would depend I think, what it, what it was.

Megan's frank "just can't be bothered" and "I know I should care but" can be understood as a light-hearted assertion, even defence of apathy. Other interviewees who said they would consider taking part were often attracted by feeling better informed rather than changing services.

Chloe: I suppose going to the meetings and that, ken, about hospitals and the talks about them. That would be quite, good. Find out what was happening.

Even Lisa, who talked about some very unhappy interactions with the NHS, emphasised learning and hearing reasons rather than changing things she was unhappy with, working with the evocative imagery of being "just in the dark" or "kept in the light".

Lisa: Just being able to get your opinion across and get, getting feedback from them instead of just being somebody that's just in the dark basically. You say your piece to whoever and then that's it, you dinnae hear nothing else, to have a, a response and a comeback, that would be quite good. To understand more what's going on and to be kept in the light basically.

The local mechanisms of involvement, when presented to interviewees, were understood in practical terms as labour (requiring time and commitment) but as an opportunity to learn as much as to influence. This resonated with how PPF members described their roles, and once again revealed the extent to which my (activist) assumptions seemed out of kilter with local understandings.

In an effort to explore the topic further in a non-accusatory fashion, I asked interviewees why they thought that there were so few young people involved. David's response placed the onus on the lack of advertising of the Forum by the NHS:

David: Well I didn't know there were meetings, so. If you don't know about something then there's no way that you can go is there? So it's got something to do with advertising, or publicity.

Other explanations focused on a lack of confidence to express opinions, contrasted with the assertiveness of older generations. As Andrew suggested: *"I think it's mair an old person's thing cause young people dinnae have the confidence to just go along and say what they think. But older folk just dinnae really care"*. However, most felt that it was because of young people's minimal interaction with the NHS.

Lisa: Probably because a lot of young people dinnae, dinnae need to use the NHS, as often as, well I know that sounds terrible but older like over 30 or whatever... So it's maybe just that a lot of under 30s or whatever dinnae, dinnae suffer enough.

Chloe: Em, I suppose we're not really, not really, not really, I wouldn't say bothered but, again if there's people that aren't really frequenting doctors you know, they're not really there, like if they're going once maybe twice a year, you're not too bothered. You know, you're in and you're out, for what you need, and that's it.

This mundane, pragmatic relationship between fairly healthy young people and the NHS became a recurring theme within the data.

There are, of course, other mechanisms through which young adults can influence the NHS, either through formal political participation, or through the 'everyday politics' (civic associations, voluntary groups, protesting) that Dalton (2008) argues is increasingly attractive for young people. However, while some of my interviewees' responses suggested an NHS-centric problem with participation, few of my interviewees reported playing any role in community groups, including leisure activities. The only exception to this was David, who worked part-time as a sports coach and was active in a regional network of coaches. He told me enthusiastically how he had become involved with the organisation, and was rushing off after our interview to arrange the association's Christmas dinner. Laura mentioned being involved with a range of civic

activities through school, but said these had all finished when she left school. She reflected on the challenges of trying to find solutions for the community as part of the pupil council at school:

Laura: But for as much as you pushed for more, more facilities for young people, it was just I think people are like even myself, you're completely stuck for ideas. Like what people want to do.

Other than that, my interviewees talked about their lives almost exclusively in terms of work (or job-seeking), family and friends. Family was a large part of most of the young adults' social worlds, particularly as most had lived in the area all their lives. Amy, who had a young son, said she had tried to go along to toddlers' groups or keep-fit classes:

Amy: No we did have, we did go to the toddlers group once, and I got left with all the children while they went for fag breaks. So that never happened again. I was the only one silly enough to stay with them all while everybody else is just drinking their tea. So I just gave up after that.

Amy's account repeatedly emphasised that the world outside trusted networks of friends, colleagues and especially family was viewed with some suspicion. However, interviewees did not express sadness for the absence of Putnam's (2000) vision of community. All my interviewees had grown up in the region, and many were Rivermouth residents from birth, often still living in close proximity to their family, and describing good social support networks.

In an effort to explore whether my interviewees were politically engaged, I asked simply "are you interested in politics at all?" and "have you ever voted?" Most answers to this divided into two groups; the majority, who were not interested and had never voted, and those who were not interested but had voted because of family pressure. Several interviewees became monosyllabic on the topic, despite my attempts to pose the questions lightly:

ES: Em, do you vote?

Amy: No

ES: Have you ever voted?

Amy: *No.*

ES: *Why's that, do you, like I mean lots of people don't vote, but-*

Amy: *I don't know. I think they're all just as bad as each other.*

ES: *Okay. Do you think you ever will, you know, or do you just sort of see that, not changing?*

Amy: *No, not in the future. For a good while anyway.*

Laura's response reflected two themes which recurred in many of the interviews: a lack of confidence in one's own knowledge about politics, and a willingness to be guided by the decisions of family members:

Laura: *I think, the whole thing just sort of confuses me. Like, unless you go, like properly into detail, I just can't see, like, the difference between the parties. Like obviously they've got like totally different aspects on politics, but unless you have an interest in that issue, everything just seems, like, just, it just doesn't make sense to me to be honest with you! [laughs] I, I've never voted, but em albeit I wasn't quite old enough the last elections, but, in all honesty there's nothing pushing me to vote. Like there's nothing, when you're watching the news, nothing sort of sticks out.*

ES: *So there'll be an election in May or June...*

Laura: *Yeah, I think, in a way I don't want my vote to go to waste. And I'd rather go in and vote, I don't know. Like, we've had these discussions at school, like at uni, how people have like fought for this right to vote, so even if you go in and you like rip up your ballot paper then you've at least used your right to go in there and voice your opinion. Whether you do or not is completely up to you. Em ... my Mum and Dad vote Labour, and my Gran votes Labour, and I would maybe vote Labour just because [laughs]. Like in a, I wouldn't really know why I was voting for it, though. Which, obviously that's wrong on my part for not, sort of getting to know, like, like into detail but, it's nothing that's really interested me.*

One interviewee, Andrew, described being even more influenced by his family: simply voting for who he was instructed to by his mother.

Andrew: *Yeah. She, she strongly believes in voting and she, I can't remember who she asked me to vote for, it was a weird name I've never heard of them before but she asked me to vote for them. Eh so I went and voted for them eh and the second time I voted for them*

again, em. Both times they werenee elected but oh well, but if it wasn't for the fact that I got my own house I would probably still be voting as well. But I don't have any interest in it.

Rachel was the exception to the lack of interest in elections. Like Andrew, she came from a family of party activists and tended to vote for her mother's party of choice. However her commitment to voting was firmly rooted in a belief that it could change things for the better:

Rachel: I dinnae see why people dinnae vote because if more people voted then the country maybe could be better! [laughs]... and my mum's quite a, a Labour woman eh. She has eh the signs and a' thing in the garden so I usually vote for [laughs] who they sort of go for, you ken?

Reports of young people's lack of interest in formal politics are so commonplace now as to be clichéd, but there was nuance in my interviewees' accounts, including embarrassment, confusion and the continued influence of family party loyalty, as well as active rejection.

I asked interviewees about their local area, and – in an effort to bring up local politics – whether there was anything about it they would like to change. In some cases I used the prefix 'if you were in charge' to open up possibilities outwith the conventional parameters of local politics. One or two interviewees talked about things they would like the council to do differently, including Rebecca who had strong views on the council's failure to develop empty spaces of land. When I asked Rebecca whether she would ever contact the council about this, she was first scathing about the idea that they would listen, and then recalled times when she had responded to consultation letters.

Rebecca: Nah. Ha! Em, nah, I wouldnae. When, what difference would it make eh? There's only me, they're not going to take one person's opinion. So, I wouldnae, nah. If I'd been asked about it I maybe would say something, but I wouldnae actually go and write a letter to them, eh. But if I had got asked about it then I would say. I mean I've had letters from the council before asking what we think and things like that and I have mentioned it on the letters that I think a lot of, they're needing to stop building houses! Start building things that are actually useful to people. Or if you're going to build houses, build council houses, no' houses for people to buy.

This complaint moved from the personal (a play park for her son) to the macro (town planning policies and the provision of social housing) in what I felt was a sophisticated fashion. Laura similarly talked about activities for young people, and the police's attitudes to them.

Laura: I think, and this is purely going back to when you were at school, there was, there was just nothing for young people. Em and like there's nowhere for you to go so if you meet on the streets you're automatically like a delinquent, and the police are there, straight away. And that was something which, like I was, you were never out to cause trouble, like I was not a person like that. But if you were seen on the street with a group of your friends, then you were like automatically a stereotypical young person who was like, had a bottle of Buckfast in their back pocket.

Other than that, most complaints were phrased in terms of other members of the public, and interviewees expressed doubts about the state's ability to resolve these problems:

Andrew: Eh this, this area, this small area here, it it's fine... It's outside this area that's the problem. Eh wi' gangs and fights and, it's getting a bit out of control... But I don't think anybody could really change that. They're no' going to run about skelping⁸ everybody's arse.

Chloe: Eh, I do, I like it. But, like I like this sort of area. But it has went downhill a wee bit... Em, a lot of drug addicts and things.

David: What would I change? I think it actually is that mentality thing really. If you could, but you can't really change people's attitudes just like that. Or their way of thinking. Em, I suppose if they were happier, that would be good. But it's just so difficult to change.

David, Andrew and Chloe identified social problems, broadly defined, but struggled to understand how the state, or "anybody" could change them.

Bearing in mind Dalton's reflections on changing patterns of political activism among the young, I also asked about commitment to or interest in other causes or campaigns. After expressing a lack of interest in politics in a previous answer, Rebecca surprised me

⁸ smacking

by revealing that she had voted for the first time recently because she was very concerned about green issues.

Rebecca: *Em, I wouldnae say I was interested in politics. I wasnae, but I'm maybe slightly interested noo. See I'm, I'm interested in this, this climate change thing the noo. Em, my mum and dad go mental at me, cause I talk about it a' the time. Em, but I am, I'm really worried about this. I think that em I think they're needing tae dae more. I don't think they're doing enough. Seemingly, it was on TV the other day, they had a big budget, more than what they usually have, and Gordon Brown had said that they'd only spent 10% on this climate change. And so that budget basically got wasted. Whereas, if they tried to make a big difference, for what's seemingly been said, I mean what's going on, cause I mean all the ice and everything's melting and things like that. It is, it's major. I don't think actually a lot of people realise how bad it actually is. And he doesnae seem to be doing anything so I say kick him out the door [laughs].*

However, this enthusiasm, like the animal rights focus which several interviewees highlighted, didn't prompt engagement with formal politics. Rather, the available public roles which we discussed were, for most interviewees, quietly avoided. This is not to fall back on the familiar stories of youth apathy. Rebecca nagging her family to change their light bulbs, like Megan's commitment to taking unwanted clothes to specific charity shops and Laura's payroll giving to a breast cancer charity, remained in the privatised realm. It was here, therefore, that I began to look for health and health service-relevant political acts.

EVERYDAY PRACTICES OF HEALTH & SERVICE USE

Given the overwhelming absences (of experience, of opinions, of interest) in my original conception of young adults within the formal top-down mechanisms of public involvement, I had to rethink elements of my understanding of voice and choice within the Scottish NHS. Reluctant to conclude simply that these mechanisms do not engage young adults, and with my supervisor's suggestion to 'ask what they *do do*' (see also Skelton & Valentine, 2003, p. 118), I started instead a conversation with my interviewees about their experiences of health and health services. These discussions were fascinating. Often, anecdotes about service use familiar from my own use of the NHS – such as the quiet persistence required to get an 'emergency appointment' with

the GP – enabled me to see ‘commonsense’ aspects of the NHS in a new light. At other times my lack of local knowledge, and consequent ‘outsiderness’, presented itself baldly. These instances sometimes transformed my understanding of apparently concrete ‘facts’ about Rivermouth, as when one interviewee, whose home seemed to me in my car to be some distance from the surgery, told me about a path across wasteland which made it by far the nearest practice. Recognising both my own lack of knowledge, and the preconceptions with which I approached these interviews helped my attempts to grasp my interviewees’ situated perspectives.

In terms of healthy lifestyles, just under half of the young adults I interviewed told me they smoked (six of 14). The national average for over 16s in Scotland is 29% (NHS Scotland, ISD Scotland, & ASH Scotland, 2007). What was more interesting from the point of view of my study was the way my interviewees responded to this question, which either came up spontaneously or was posed in a short section of the interview covering lifestyle issues. Everyone seemed sheepish about this, and several told me they had had help from the NHS to try to stop. Similarly, most of my interviewees said that they drink excessively on the occasions when they do drink (although several protested that the occasional nature of the habit mitigated the excess). Lauren was one of the more defiant when discussing alcohol.

Lauren: Aye I think I consume a bit too much... At the weekend. I'll admit it, I'm not shy about it, or I wouldn't do it [laughs].

ES: And do you worry about that health-wise, or is it not-

Lauren: It's, just the way I live and you put up with the, whatever comes along, don't you? That's, if I want to go out and enjoy myself that's the way I'm going to do it. There's people worse off than me that are going about taking drugs. I'd rather just have a drink [laughs].

A few admitted to either accidental injuries when drunk (usually mentioned laughingly) or, in more cautious tones, fighting or being attacked when drunk.

Interviewees expressed little bravado about risky behaviours such as drinking, smoking and fighting. While this was undoubtedly due partly to my being a stranger and a researcher, there was at least an awareness of societal censure of ‘unhealthy’

behaviours. This did not, however, seem to have enabled my interviewees to change them. Rebecca's description of trying to stop smoking was a good example of most people's attitudes.

Rebecca: I went to one of the classes. It was a one-on-one class. And I got, em, patches. Eh, they do work. I cannae say they dinnae work, because they do work, the only thing is you have to have the will-power to stop. And the first time I stopped I did, I think I lasted 6 month. And I did have the will-power to stop. But em, I can't even remember what happened. I think it was, I was actually going out drinking a wee bit more, then. I was going out every weekend. And, when you go out drinking it's a lot harder to stay stopped. Cause you see everybody else smoking. So that's why I started again. Eh, but the last time I tried to stop, when I went to a class, I just didnae have the will power, eh, cause my son was going through a bad stage as well eh, I think he had, he was just over two. And it was like terrible twos eh, and he was just a nightmare, constantly, all the time. So stressed all the time.

It comes as little surprise to those familiar with health improvement literature to hear that 'life gets in the way' for Rebecca, as for many stressed mothers living in poverty (Graham, 1994). As we discussed their experiences with the NHS and their worries (or lack of) about their health in the context of their lives, lifestyle decisions seemed, if not always 'rational', certainly 'reasonable' (Backett & Davison, 1992). That is, ostensibly short-sighted or 'bad' decisions can become understandable when considered in the context of one's life, with associated challenges, opportunities and socio-cultural norms. As the objects of considerable NHS efforts at behaviour change, this tension between what we know is our best course of action as responsible health service users, and what we want to do, right now, as situated human beings, takes on a renewed relevance.

Interviewees had varying levels of experience with the NHS. Three reported long-term conditions (asthma, a thyroid problem, and blood clots) and three had worked for the NHS as trainee nurses, healthcare assistants or administrators. Much of my interviewees' service use was not the life-or-death stuff of grand narratives about the crucial role of health services in our survival, but rather the day-to-day business of keeping bodies and minds ticking over, particularly with regard to their fitness for work. This less fraught relationship with the NHS makes for a fairly abstract commitment to its quality. The resulting "loyalty" (Hirschman, 1970) was pragmatic, understated, and

sometimes unthinking. When asked if there was anything he liked or disliked about his GP practice, David responded:

David: *Not really, because when you go to a health centre or whatever, it's just there to, you know, find out what the problem is, get a solution, and, just get away. It's nothing, it's not like you have to be attracted to it, it's just, you've got a problem, go to the hospital, go to the health centre, get it sorted out, and get back to living your life.*

Visits to their own GP, as well as being in most cases only a couple of times a year, were largely reported as being for mundane issues which resulted in no further action or a course of antibiotics or painkillers. Several interviewees worried, before the tape recorder was switched on or during the interview that they didn't have enough experience, or interesting enough experience, to be worth speaking to.

The majority of my interviewees were occasional service users who, almost without exception, said they got what they needed from the health services they encountered. "*Aye, that's/they're/it's fine*" was by far the most frequent initial response to my questions. Taken together, my interviewees' accounts described mundane, occasional service use. While this is a common pattern of service use for much of the population, it is one rarely discussed in policy discourse. Much of my interviewees' stories seemed so obvious to me, having grown up in the same health system, that it was difficult to attend to as new or worthy of attention. However, my final interview, with Lisa, a recovering heroin addict, described a number of troubling experiences with GP practices which made me reconsider my other interviewees' descriptions. As something of an extreme case (she had been removed from a practice list for allegedly missing appointments, had been made to cry by her most recent GP, and described difficulty getting a recent diagnosis) hearing Lisa's experiences enabled me to re-evaluate (in some cases to notice for the first time) similar, if milder, tales, and crucially my interviewees' responses to them. This is not to detract from the overall satisfaction reported by my interviewees. However, it counters the assumed passivity of behaviours which, at least from an organisational perspective, cannot easily be understood as either 'voice' or 'exit' (Hirschman, 1970). Here I will discuss four types of action which I recognised in my interviewees' accounts of everyday health service use: avoiding 'bad' GPs, making appointments, negotiating diagnosis, and dealing with 'trouble'.

AVOIDING 'BAD' GPs

While it is possible to move GP practice in the NHS, few of my interviewees had done so. Most of them had been with their current GP practice “*always*”, since birth or before. There were some quite remarkable tales of “loyalty” (Hirschman, 1970). Andrew explained that he, his parents and his grandparents were all registered with a practice which was not the closest to his own home, or to his parents’ home, but to the home his mother had grown up in. I asked Laura, who had registered with a doctor in her university town for one year before moving back in with her parents, why she had decided to go back to the practice she had been with since birth.

Laura: It wasn't even something I thought twice about. I just, I've never had any negative experiences... But em, it wasnae really an option. I didn't even think twice about going to find somewhere else, so.

Other interviewees said they had left the area but stayed registered with their previous practice, keeping their parental home as their permanent address. Those who had moved practice reported that they had done so due to leaving town or, in Lisa’s case, because she had been removed from a practice list for allegedly missing appointments. Only one of my interviewees said they stayed with a practice because of what I would describe as enthusiasm about the service. At two separate points in the interview Rachel became emotional discussing the support her GP practice had given her family during a difficult period, and her gratitude to them.

However, while not considering proactively changing GP practice, most interviewees described preferences to see particular GPs within the practice. Highlighting the non-bio-medical aspects of patient care (Mol, 2008) almost everyone who expressed a preference justified it with reference to interpersonal factors:

Rachel: She's a friendly doctor, eh? And if you go in and tell her what's wrong wi' you, she em, she'll sit doon and she'll, and she'll try and, cause she's quite young as well so she kindae understands where you're coming fae.

David: I just like to go to that doctor because I like know him... He's quite cool. Like, not cool, he's no' cool, but he's an alright guy.

Lisa: *Silly things, like he sits and he looks at you when he's talking to you and he listens. Where others just sit and type or write.*

Where these aspects of the consultation – patience, warmth, familiarity – were absent, they contributed to my interviewees' dislike of other specific GPs in their practices.

Rebecca: *It's weird it's like she's always got that right grumpy look, a' the time. And you go in and a' and you try to speak to her, sometimes she makes you feel a bit, uncomfortable. Because it's like she's no' really got time for you, sort of thing, eh.*

David [on the doctor he avoids]: *She, she's just quite cold. She doesn't really have much, personality.*

These varied preferences – smiling, being attentive, understanding, even 'alright' – point to the emotional labour required of GPs beyond the medical and administrative aspects of their role. However Lisa's reference to "*silly things*" here, and other interviewees' use of "*just*" to qualify their preferences were typical; these preferences were deeply held but interviewees seemed cautious when expressing them in the interview. Literature tells us that these factors are not only consistently important to patients, but are in fact integral to the bio-medical processes which academics (and perhaps patients too) feel more comfortable to classify as 'good' or 'bad'. Mol, for example, argues for recognition of how care is 'done', and that "the way professionals in day-to-day care practices engage in doctoring and nursing, in tinkering with and calibrating care, deserves some back-up" (Mol, 2006, p. 411).

Crucially, everyone who expressed a preference for or against one GP had some sort of tactic for seeing or avoiding that person. Interviewees at the practice with the unpopular Dr Jones expressed stronger views (Lisa: *Her I try to avoid at all costs. I dinnae like to see her*). Ryan, who had recently moved to a practice, said he would like to keep seeing the same doctor but that "*Aw, I cannae even remember her name!*" Most said they'd ask for an appointment with a named GP, but if it meant a longer wait, several would take anyone. Several were a little more proactive:

Rebecca: *If I phone, I dinnae want to say 'I dinnae want Dr Jones or Dr Stevens.' I'll just say, and if she says 'Dr Jones' then I'll just say 'oh no that's no' any good'... Make an excuse. You dinnae want them to make it out eh that you're no' actually wanting them, cause then they*

might say 'oh what are you no' wanting them for?' So I just say 'have you got another time?'

ES: *And would you not like the opportunity to say?*

Rebecca: *Nuh.*

ES: *Nah?*

Rebecca: *Nuh. [Laughs]. I'll just avoid them.*

Rebecca was willing to go to some lengths to avoid two doctors she didn't like, but also to avoid this being registered as any kind of feedback. Dr Jones was mentioned as the doctor they avoid by almost every patient from that practice (except for Laura, for whom it should be noted she was the preferred GP, as she was "to the point"). Megan remarked on this unpopularity:

ES: *Are there other doctors that you would prefer to avoid? You don't have to name names or anything.*

Megan: *Em, probably, if I could. And it is, it's always the doctors that are most available, that's the [laughs], that's the problem. Whenever you phone it's always like 'aye, I can give you them', and you're a bit like 'em, right.'*

The lengths to which some of my interviewees would go to avoid unpopular GPs is an interesting example of informal or unsanctioned personalisation by service users. Interviewees were knowledgeable about which GP to see, and had tactics for seeing their preferred doctor. This adds important detail to Leadbetter's account of the "old script" in paternalistic services: "phone GP, make appointment, visit surgery" (2004, p. 38). This service user activity can be understood as "subversive" (Prior, 2009) of policy; exhibiting service preferences which do not fit into managerial drives for efficiency, and avoiding one's preferences being utilised as constructive feedback. Although there is no way to be certain of this, Megan's comment about the greater availability of unpopular doctors hints at the possibility that within a service provider, the functioning of informal patient choice between individual professionals can create 'sink' GPs, in the same way that we see formal user choice create 'sink schools' or 'sink hospitals' (Le Grand, 1991). Here, an unpopular health professional is less in demand. He or she becomes disproportionately likely to see occasional users and urgent cases, where patient

inexperience or distress may create more fraught encounters. This perpetuates a vicious circle for a doctor's reputation.

'EMERGENCY' APPOINTMENTS

Another example of the way that my interviewees got what they wanted from the NHS was around the use of emergency appointments. However, this was so rooted in commonsense knowledge about the process of going to the doctors (my own knowledge, as well as that of my interviewees) that it was less self-evidently 'action' at all. At both the practices I recruited through, the practice information states that a number of appointments are held back each day for emergencies, and allocated to patients who phone first thing.

"Urgent appointments: If you have an urgent problem, you will be seen on the day of request if appropriate. Your call will be triaged by our Nurse Practitioner in the first instance. Please try not to ask for an urgent appointment unless you feel this is absolutely necessary."

However, in many of my interviewees' accounts, phoning on the day was presented as the main, 'normal' way of making an appointment.

Rebecca: If you really need an appointment if you phone at eight o'clock, as soon as you get up in the morning, usually they do have some sort of cancellation that day. Might not always be the doctor you want, but, if you really needed the appointment you could get an appointment, wi' another doctor eh.

Chloe and Megan told me they couldn't call in the morning because of their shift patterns at work, and as a result chose to make appointments in advance. However, calling on the day was still a familiar option.

Megan: I had phoned to make it for like my day off. I generally, I've only been able to get one the day I've wanted it if I phone at like 8 o'clock or something.

Chloe: Mm, it usually is a few weeks. Like unless you phone like every day in the morning. But, usually yeah a few weeks you have to wait.

GP receptionists are increasingly recognised as performing a range of vital emotional and quasi-medical tasks beyond the administrative work they are associated with (J. Ward & McMurray, 2011). Rachel recounted an anecdote which suggested the tension between practice staff trying to maintain a system of emergency appointments through ‘unofficial triage’ (Coulter & Elwyn, 2002), and patients trying to use this as the main appointment system.

Rachel: *Well I got up at eight that morning and I phoned and I got an appointment, I think it was in the afternoon. Em it was for Dr Green I got and I went down at three o’ clock eh.*

ES: *And how do you find the reception?*

Rachel: *The reception, it, it depends I think. Because sometimes, you could phone in the morning and you wait a long time on getting on the phone. And sometimes, it depends what receptionists on they’ll maybe ask you why are you wanting an appointment, is it urgent, you know. Like you get a whole list of questions fired at you eh, cause when you’d rather just like get your appointment and see the doctors. Ken even if it’s just like to ask the doctors a question, you ken, it’s, it’s no’ a case if it’s an emergency, if somebody’s wanting to see a doctor, they’re wanting to see them for a reason eh.*

Unhappiness at having receptionists assess one’s neediness as a patient was also related to my interviewees’ feelings that they were responsible service users. Emma described being far less reluctant to visit the GP as she got older.

Emma: *Em, I don’t know. It’s just before, when you’re younger you don’t really bother what people think. And then as you get older always think I wonder what they doctors are thinking looking at my notes, saying there’s always something wrong wi’ her!*

For Emma, becoming more responsible as an adult service user equated with using the GP less often. Therefore when she did decide to phone for an appointment, to be confronted with “unofficial triage” was described as unfair.

NEGOTIATING DIAGNOSIS

A further area where my interviewees described taking action in the NHS was in negotiating diagnosis, or indeed in deciding to abandon the search for a GP’s diagnosis. In contrast to the treatment focus of much health policy discourse, diagnosis constituted

the main focus of my interviewees' accounts of health service interaction. It was this stage that interviewees seemed to find most worrying, and it was mostly here that negative experiences occurred. Diagnosis is a crucial process in health care interactions, which is imbued with questions of control and knowledge: "For patients, diagnosis can provide personal, emotional control by way of knowing what is wrong. For medical professionals, diagnosis also provides control by mastering the knowledge of the problem at individual care level" (P. Brown, 1995, p. 39). Once a diagnosis is reached, individuals can draw on resources of information and support from services and fellow sufferers, and may be reassured about the legitimacy of their worries. However, in the uncertain terrain pre-diagnosis, my interviewees either negotiated a solution (drawing on resources of family knowledge and the internet, and making repeat visits to different individual health professionals until the problem was solved) or chose to opt out of this process (perhaps worrying quietly about an ongoing symptom, or perhaps giving it little thought until the moment of our interview). This was an exertion of agency, but it bore little resemblance to assertive service use. This was interpersonal, informal and frequently unsatisfactory for my interviewees.

Megan's description of the process of trying to be referred on to a clinic for her allergies demonstrated the emotional pressures around diagnosis.

Megan: I, I got sent to an ENT specialist years ago, and he was really really good. And, that's, they [the GP practice] never ever sent me back. I went to see him once, and then they just dealt with the prescription after that. And, again, we just got stuck in a rut with the same things, and they're not helping anymore, so I did say to the doctor 'can I not go back and see them?' And she had just said like 'no, there's no point sending you back, we'll try and do things here', but every time I went back and said 'I don't feel any better', they just kept saying 'well the stuff you're on's the best you get, so you'll just have to keep it'. And it wasn't til I went and seen another doctor, and she was actually really nice, and I said to her, 'could I be referred at all to the hospital', and she actually just admitted 'well yeah, we're at a loss with you, so we're going to have to send you'.

The starting point of confirmation from a specialist is, I would argue, relevant to Megan's persistence in seeking a referral. She described the frustrations of not having her views listened to, but she continued to believe that a return visit to the specialist would be valuable. She spoke emotionally about finally seeing the specialist.

Megan: And I thought thank god. But it took ages of saying before they would actually send me. I don't, I really don't think they wanted to refer me, if they didn't have to.... And it was quite good the first time I seen him, em, when he looked up my nose and things he said that you should have come to me years ago. And I, I really could of greet⁹ because I, really, it wasn't in my mind.

The relief (“I could of greet”) of diagnosis, as confirmation of the legitimacy of her concerns, had for Megan, retrospectively justified her persistence in speaking up and asking for a referral.

This agential tactic – repeated visits to different GPs until they reached a diagnosis they found satisfactory – was described by a number of my interviewees. The process began earlier, reflecting Locker’s (1981) work on causal theorising about problematic symptoms in everyday life. Wyke concurs that

“It is clear that it is not usually the illness itself that bring patients to professionals, but rather their theories as to what the illness is, or might be. Thus formal consultations are typically used to confirm diagnoses, to help decide between several potential diagnoses, or occasionally to ask doctors what the problem is.” (Wyke, 2003, p. 56)

Lisa described the process of getting a diagnosis of gallstones.

ES: *So if you had to keep going back, was the diagnosis quite complicated then?*

Lisa: Well first of all, with the doctor I don't like, she told me I was just clinically obese, and you need to lose the weight and start eating healthy. Tellt me to give up the cigarettes and all the rest of it. The second doctor told me I had eh ulcers, stomach ulcers, em, and then it wasnae until I seen Dr Taylor, and he said 'no, I think it's gall bladder'.

Later in the interview, Lisa revealed that she had guessed this eventual diagnosis earlier in the process:

Lisa: My auntie had a gall bladder out in the June, and this is when my pain started coming and causing me nothing but trouble, so my auntie was like 'I'm telling you it's gall bladder,

⁹ Greet = cried

it's gallstones', so I'm on the computer, googling 'pains in my side' and that's one of the things that came up was gallstones, so I read about that and I went to the doctors and she said 'no it's not gallstones', this is when I was told I was obese. 'No it's nothing like that, it's just because you're clinically obese, you're needing to lose weight.'

This combination of information from family and information from the internet is characteristic of the way that most people draw on online health resources. While American research suggests that a Google search is the first step for many people puzzling about a health problem (Fox & Rainie, 2002), it supplements and does not replace existing sources of information (Nettleton & Burrows, 2003). While some commentators point to the transformational effects of online health information ("Medical knowledge is no longer exclusive to the medical school and the medical text; it has 'escaped' into the networks of contemporary infoscapas where it can be accessed, assessed and reappropriated" (Nettleton & Burrows, 2003, p. 179)) Lisa displayed considerable reflexivity about this information. Later in the interview she remarked "*I could have been reading anything. Ken? The internet's no' that a fair place*". What Lisa described as making the difference was the agreement of her auntie's suggestion and information she found online (and it is likely her online searching was shaped by her prior knowledge of her auntie's condition).

However, Lisa had used this information to support her persistence in striving for a diagnosis, and not as ammunition for a debate with her GP. When I asked her how she felt about the process of getting this diagnosis, she described using a combination of family knowledge and online medical information not to assertively make her point but instead as a reason to keep returning to the doctors.

ES: *How did you feel about all this?*

Lisa: *Annoyed. Because I was telling them the symptoms and the symptoms I've got are the symptoms that I'm reading off the computer. At one point I was actually going to print it off and take it to him and say look, there you go, that's what I've got. But, I never done that.*

ES: *Why not?*

Lisa: *Cause he agreed to send me for a, well on the third occasion, with Dr Taylor, he was like right, okay, we'll send you for, a scan. An ultrasound. That was that.*

ES: *Why do you think you decided never to sort of, I don't know, take all the bits of paper and say here, like-*

Lisa: *I, cause I didnae want, I didnae want to be coming across as being cheeky, and trying to show them to do their job. [laughs]*

Lisa described managing the impression the doctors had of her despite being convinced about her diagnosis. The process she described can be understood as pretending to be less knowledgeable than she was to avoid alienating the GP whose formal diagnosis she needed.

Other interviewees recounted tales of diagnosis where they had not been persistent, and which remained unresolved. Emma told me about an evening when her ear started bleeding heavily at a party. Illustrating the galvanising effect of social support, her neighbour persuaded her to go to Accident and Emergency the next morning.

Emma: *All [the doctor] done was give me antibiotics and ken I thought, na, am I not getting to go to the ENT clinic? Cause I've got problems with my ears already eh, but it was a coloured doctor eh, ken I couldnae really understand her eh. Ken when you're trying to tell her she's like have you been fighting? And I was like no.... I dinnae ken how it happened. But they just gave us antibiotics and sent us home.*

Here, Emma, with past experience of going to the ENT clinic, knew the outcome she wanted. She described communication problems, possibly resulting from her own prejudices (“*a coloured doctor*”) but also aggravated by the doctor’s assumptions about Emma (“*have you been fighting?*”), and her response was to leave, dissatisfied. However, she described still having the physical symptoms, and persisting in her search for a diagnosis.

ES: *And so did you go back to your GP to talk through-*

Emma: *I'm gonnae have to cause I can't stick my ears under the water. And I don't think that's right, eh? My best pal's mum's a nurse eh, and she was like that 'you should be able to stick your ears under water'.*

As yet, Emma hadn't pursued the diagnosis but, drawing on accredited knowledge within her social circle, she planned to do so. The marshalling of information from trusted sources was crucial here, as very few of my interviewees talked about feeling confident as an individual to develop an alternative 'story' about their ill-health. For example, Rebecca talked about feeling dissatisfied with a recent diagnosis:

Rebecca: I think, to this day, I'm still no' convinced. I mean I'm no' a doctor so I dinnae understand, and the thing that I said to my mum is, if it's my spleen, why is it the first time I'm feeling it? ... It's different if you ken what they're talking about. I mean I don't even ken what your spleen is, never mind anything else eh? [laughs]

This causal theorising was a common factor of accounts of ill-health. However, it was repeatedly described as happening with family (particularly mothers) and not with health professionals. Asking GPs for explanations was not mentioned.

The salience of diagnosis is well-understood and theorised within the sociology of health and medicine. Literature tells us that diagnosis is a search for explanation, as well as for treatment (Locker, 1981). Sociological accounts of the transformation of health information online and with NHS 24 (the Scottish equivalent of NHS Direct) suggest that patients consult a range of very different sources in their attempts to make sense of symptoms (Nettleton & Burrows, 2003). However, the patient's role within diagnosis as one manifestation of agency (even control) is only minimally considered in policy-oriented research, where choice of treatment (as exit) or complaint about failed diagnoses and treatment (as voice) are more commonly acknowledged. My interviewees revealed negotiating diagnosis as a nuanced, subtle business, but one in which self-awareness and agency were nonetheless present. Despite use of online information and NHS 24, trusted information from friends and family – especially where this included health professionals – remained central in my interviewees' decision-making.

DEALING WITH NEGATIVE INCIDENTS

While interviewees expressed few strong feelings about health services in general (in answer, for example, to "how do you find your practice generally?" or "how happy would you say you are with the NHS here generally?"), most of the women had stronger views

on particular incidents where things had gone wrong. (It is important to reiterate here that the way interviewees were recruited may have increased this number). There was a clear gender divide, with men having both fewer interactions with the NHS overall, and reporting very few negative interactions. Laura recounted an incident from her childhood.

Laura: Em, and that was my own doctor I saw and she was sort of, sort of just brushed it off as I'd just knocked it or something but it was, it was so, like a definite cyst, like you could tell. And when I saw the second doctor, em, it was like a case of me walking in and she was, like she noticed it straight away and said 'that's a cyst' and referred me up to [the hospital] to have it like surgically removed.

Lauren reported a delayed appointment where she was unhappy with the diagnosis and the GP's manner.

Lauren: So I get to the room and I told her that I had been coughin' and spewing up blood again, and that I, my weight kept going up and down and I was down to a size 10 at the time, and she says 'oh, I don't see', I, I don't remember her exact words. Pretty much saying to me no, I don't believe you. And then I says em yeah, and I'm coughing up blood blah blah blah. 'Are you sure about that?' My reply to her was 'well I've been waiting, I'm 35 minutes late for my appointment, I've got to get back to work, I'm not going to be sitting wasting a doctor's time'.

Lisa, a recovering heroin addict who has been 'clean' for some years, became tearful as she described how a new GP responded to her history.

Lisa: As soon as she found out I was a heroin addict, well, ex-heroin addict, she wouldn't touch me. She stood at arm's length and she made me feel so awkward I left the surgery in tears. Because the way she, like she asked me about my past, and I told her, and as soon as I said that it was like a totally different person.

Crucially, none of the negative incidents described had resulted in any formal action being taken by my interviewees. Although Sarah still asserted determinedly that she "is gonnae sue", most of my interviewees were very clear that they would not complain about their treatment. Even where tales of trouble were far more prominent (particularly for Lisa, Laura and Sarah), no formal action had been taken.

Lisa: I was actually going to complain, about, the doctor who made me feel terrible. About my past and stuff, I was gonnae complain about her. But, I, I, I never. I don't know why I never, because I was determined and, cause she had me crying and everything. That's hard for me, to cry, something like that I just, normally I just brush it off but she did make me feel that small.

After Lauren's experience she had gone to the reception desk to complain and had been told to write a formal letter to the surgery, but never had.

ES: What would make you send that letter? Like, or what would have made you write the letter with all the details and, because you said you don't have time but-

Lauren: If I had, if I had enough time that's what. I think it was because after a couple of days I thought there's no point if I do that anymore... and if they had a quick form it would have been right in, there would have been no doubt about it. But, just, sometimes it's no' worth the hassle.

Rebecca and Rachel both said they had chosen not to complain about negative incidents, with Rebecca preferring to "rant and rave" at her mum. Instead, my interviewees favoured informal, even subversive strategies (as discussed above) to avoid the offending individual in future.

These tales of "trouble" (Cantelli & Regis, 2009) in interactions with health services, were, in Schegloff's (2005) terminology, "complainable", rather than complaints, in that few had been articulated beyond 'moaning' to close friends and family. Laura's statement that she had never had negative experiences with her GP, followed by her tale of the troublesome diagnosis of a cyst on her lip, was an example of the interview as apparently one of the first opportunities for these young adults to reflect on their health service use. None of my interviewees remembered being asked their views on the NHS before. Eliasoph (1998, p. 19) argues that where interviewees haven't reflected on issues before, interviews: "may encourage respondents to speak in uncharacteristically serious ways about issues that they usually treat flippantly, or ironically, or do not discuss at all." Likewise, it is not the case that "when the moment comes for expressing views, individuals will simply scrutinise the internal mental states that they have brought and will report on them" (Davies, et al., 2006, p. 200). In this case, I would argue that Laura's situated, practical memories of interactions with the NHS ('that time I had x

problem') hadn't, until the moment of the interview, been articulated into what we could call 'service knowledge'. Barnes argues that storytelling

"is not simply a process of recounting 'what happened'. Through recounting the story the teller is making sense of the experience. They are engaged in a process of reflection and interpretation for themselves, as well as a purposeful performance directed at the hearer." (M. Barnes, 2004a, p. 128)

This translation develops "the mute experience of being wronged" into "political arguments about justice" (Young, 2000, p. 72).

While the usual explanations focusing on resources of confidence and information to complain are relevant (Allsop & Jones, 2008), I would argue that the limited practical importance of NHS encounters in my interviewees' lives was key to their decision not to 'go formal' with their preferences or complaints. In short, the translation of unhappiness into a more formal type of service knowledge is, I would argue, less likely to take place spontaneously where one's service use is occasional and primarily mundane. My interviewees did not anticipate being frequent visitors to their GP practices in the immediate future, and many of their health needs related to conditions which were short-term or not impinging on their day-to-day lives. Accordingly, I would argue that my interviewees could compartmentalise (or put to the back of their minds) dissatisfaction with their GP practice. This is not to belittle the discomfort of their health issues. Even in cases where an unhappy interaction with the NHS was continuing to impinge on daily life (as in the case of Lauren being unable to put her head under water in the shower, or Megan having time off work because of her allergies) my interviewees displayed remarkable patience. A more frequent or experienced health service user would be confronted more often with awareness of the problem, and perhaps opportunities to articulate it as unacceptable.

AVOIDANCE, RESISTANCE AND EVERYDAY CREATIVITY

My interpretation of the accounts I heard from my young adult interviewees is that they firstly *avoided* playing a public role within health services, and secondly, exercised their agency through *everyday creativity* in interactions with health services. Despite the

absence of what we would conventionally recognise as political engagement related to the NHS, young adults were not passive users of health services. It is clear that my interviewees found a number of ways of negotiating the NHS, which have not been designed into the system with the intention of 'empowering' patients. How should we understand this realm of actions, in a context where young adults are often assumed to be passive, disengaged, and apathetic? For Bloor (1997, p. 234), "the opposite of power is not its absence but the resistance it provokes". In his study of benefit claimants in the USA, Soss explains his 'hunch' that "students of political participation needed to pay more attention to the 'everyday' claims people make on governments as they try to solve important problems in their own lives" (Soss, 2006, p. 127). In order to take these everyday processes seriously, I had to put to one side my conversations with well-intentioned, considerate NHS staff and, indeed my Hirschman-influenced determination that we all have a role to play, even a duty to fulfil, in ensuring the effective working of public services. With a starting point that both participation and 'the NHS' are straightforwardly good, it was difficult to understand the actions interviewees reported to me as more than non-participation. Putting this normative bent on hold allowed me to make space for the idea that young people are faced with a range of expectations which may not correspond with their (socio-culturally shaped) understandings of how to behave. This allowed me to explore potential theoretical avenues which had hitherto seemed excessively dramatic in comparison to the understatement of my interviewees' accounts.

Scott's (1985, 1990) 'weapons of the weak' and De Certeau's account of everyday creativity take as their starting points, respectively, the domination of a group by repressive landlords in non-democratic contexts, and "contemporary culture and its consumption" (de Certeau, 1984, p. xxi). Despite the diversity of subject matter, there is common ground in their interest in opposition to hegemonic power, and Skelton and Valentine (2003) draw both into their discussion of young D/deaf people's politics. Scott's (1990) ethnographic study of peasant culture argued that in non-democratic contexts where overt displays of political power are impossible, marginalised groups are not passive, but merely express politics in ways that political science struggles to recognise. "The realities of power for subordinate groups means that much of their political action requires interpretation precisely because it is intended to be cryptic and opaque" (Scott, 1990, p. 21). Scott identifies a number of "weapons of the weak",

grouped under headings of anonymity, euphemism, grumbling and collective representations, including folktales. I feel his work, described by Tilly (1991, p. 596) as being about “carv[ing] out little areas of autonomy in the midst of fierce discipline” chimes with elements of young people’s management of their own health. De Certeau (1984, p. xi) offers us his focus on everyday life as a realm where “users – commonly assumed to be passive and guided by established rules – operate”. He proposes that attention to practices assumed to be passive (for example reading and watching television) can illuminate the subtle ways in which ‘consumers’ exert their agency in the world around them. His concept of ‘anti-discipline’ draws heavily on Foucault’s (1979) understanding of tightening discipline within society:

“If it is true that the grid of ‘discipline’ is everywhere becoming clearer and more extensive, it is all the more urgent to discover how an entire society resists being reduced to it, what popular procedures (also ‘miniscule’ and quotidian) manipulate the mechanisms of discipline and conform to them only in order to evade them, and finally, what ‘ways of operating’ form the counterpart, on the consumer’s ... side, of the mute processes that organise the establishment of the socioeconomic order.” (de Certeau, 1984, p. xiv)

For de Certeau, consumers have no terrain of their own (“There is no longer an elsewhere” (de Certeau, 1984, p. 40)) but exist within a space defined by elites. Here ‘tricks’ and ‘ruses’ allow some “elbow-room” or “space for manoeuvre”: “tactics can only use, manipulate, and divert these spaces” (de Certeau, 1984, p. 30).

These concepts aid my efforts to understand and interpret my interviewees’ relationships and experiences with the NHS. The idea that my interviewees’ actions are resistance is appealing. I find it easy to read examples of ‘gossip’ in the sharing of tales about GPs; the ‘Chinese whispers’ gathering around a GP’s reputation. Scott’s analysis reframes the often negative connotations of gossip, asserting its constructive nature as a tactic:

“There is, arguably, something of a disguised democratic voice about gossip in the sense that it is propagated only to the extent that others find it in their interest to retell the story... Without an accepted normative standard from which degrees of deviation may

be estimated, the notion of gossip would make no sense whatever. Gossip, in turn, reinforces these normative standards by invoking them.” (Scott, 1990, p. 142)

Similarly, ‘grumbling’ – “to communicate a general sense of dissatisfaction without taking responsibility for an open, specific complaint” (Scott, 1990, p. 154) – makes sense as an interpretation of a generalised expression of dissatisfaction, which fades away when questioned. I do not think it is stretching the point to extend the analogy beyond the limited realm of young adult ‘NHS talk’ into other aspects of public life (life in public). Scott’s (1990, p. 141) description of a female peasant’s possession by spirits as an opportunity for ‘anonymity’, affording a rare opportunity to speak her mind, resonated with the very different spirits at work in my interviewees’ tales of drunken nights out. Scott’s concept of resistance offers a way to understand subtle acts of agency which do not meet conventional thresholds for political action in liberal democracies.

However the usefulness of Scott’s characterisation of resistance for this project is limited by two parts of his thesis. A first difficulty is Scott’s determination that tactics such as gossip and grumbling be seen as consciously chosen ways to behave. Scott sought to explain why peasant revolts can appear to come from nowhere, in “exceptional moments of political explosion” (Scott, 1990, p. 199), and as such he understood these assertive/agentive acts through a public frame. He denied that the actions he described were rooted in pragmatic and non-calculated everyday ways of being and doing, seeing them instead as part of a collective movement of resistance. This certainly sits oddly with the actions my interviewees described to me. Tilly’s critique points to inadequacies in Scott’s explanations of the collective nature of resistance: “What are the boundaries of the relevant populations and their discourses? How do they construct, share and change their discourses? Don’t subordinates ever resist the hidden transcript?” (Tilly, 1991, p. 598). He then goes on to offer an amendment to the theory of resistance which strengthens its application in this case:

“Compliance does not consist of conscious rule following or straightforward exchange, but of pursuing personal agendas by manoeuvring among obstacles, obstacles put in place by other people and past experience. Often people share agendas, manoeuvres and obstacles; those people are ripe for collective action.” (Tilly, 1991, p. 598)

Thus the actions my interviewees told me about, which I understand as resistance of dominant discourses, are similar because many of them are negotiating the same set of obstacles. Their actions are not due to some quietly negotiated plan of action. This distinguishes Scott's work from more recent accounts of 'subversion' or 'appropriation' of policies (M. Barnes & Prior, 2009) because these, while certainly 'citizen-initiated' remain characterised by collective action by groups at the local level.

A further challenge in applying Scott's insights to this case is the nature of the opponent. What de Certeau captures is opposition to an intangible other – in his case a culture of consumerism – which forms an entirely different focus for resistance than Scott's repressive landlord. His Foucauldian understanding of hegemonic forces allows him to understand opposition to the frames which structure our lives, rather than simply the individual or group which 'holds' power. It is important to state that my interviewees did not suggest any opposition to 'the NHS', and even their opposition to individual members of staff was largely personalised. Rather, their tactics were aimed at a system which tried to structure their behaviour in a way that was at odds with how they wished to live. Likewise, de Certeau's analogy of the immigrant forced to use a language which is not his own, and yet finding ways within its confines to continue living as he wishes, prompts us to look in my interviewees' accounts for "the trajectories [which] trace out the ruses of other interests and desires that are neither determined nor captured by the systems in which they develop" (de Certeau, 1984, p. xx). The transformation of emergency appointments can be read as an example of 'everyday creativity'. Understanding the NHS's desire for its users' problems to be ordered, predictable, manageable (and for their reactions to be measured, patient, considered) as the dominant frame, we see patients not turning up without appointments to protest, or going 'inappropriately' to Accident and Emergency, but working within the confines of the system to transform 'emergency' appointments into a standard way to see the doctor, patiently dialling and redialling at eight o' clock until all the 'emergency' appointments are gone.

CONCLUSION: EVERYDAY POLITICS IN THE NHS

This chapter offers an alternative perspective on public involvement in the NHS, reached by recognising the extent to which my understanding of involvement had been produced within the frame of policy debates. Given the picture of young adults' absence from formal mechanisms combined with a picture of alternative agency within the NHS, we can revisit the hypotheses proposed in the introduction to this chapter. Beginning with the 'supply' problem proposed, my interviewees were largely polite about the prospect, but understood it as a role for someone else to play; in particular, someone more expert, or more dependent on the NHS; someone who has 'suffered'. One finding which does have some direct relevance to current structures is that none of my interviewees had heard of the PPF; the PPF's focus on recruiting through voluntary and community organisations rather than through health services contributes to this.

Turning to the demand side problems proposed, there is a degree of relevance in each of the hypotheses, with considerable variation from person to person. Overall, though, none of them adequately captures the richness of experience I heard about. The 'satisfaction' hypothesis is a good example. While most of my interviewees said they were content with most of their interactions with the NHS, there were examples both of unarticulated dissatisfaction, where the interview itself was an opportunity for interviewees to work through a puzzling or troubling encounter, and of recognised dissatisfaction which wasn't acted upon. In the latter case, perceived failures of diagnosis or service were negotiated not by an overt demand for improvement, but by working round and through obstacles encountered. Similarly, my interviewees' relative good health meant they *could* mostly compartmentalise their problems or worries about health or health services and give them little thought. Day-to-day ailments or health service needs – 'getting patched up' – were met in a business-like fashion. However, when their bodies let them down, demanding serious attention, the resultant anxiety could be overwhelming. This reveals the NHS as a disciplining force and an institution to be circumvented as much as 'used'. Diagnosis here was an obstacle to be overcome in order to access the care and the status of a legitimate victim. In this context, the assembled modes of 'involvement' evident with Rivermouth seem far removed from this lived experience of patienthood.

Perhaps more complicated is the apathy hypothesis. Literatures of youth political participation have found a range of ways to avoid seeing young adults as essentially passive members of society. Dalton (2008) argues that a decline in voting is matched by an increase in unconventional associational life; protests and campaigns diversifying to match the diversity of life experience and interest within this group. An alternative route focuses on lived politics as expressed through youth sub-cultures; self-expression as politics (Riley, et al., 2010; Skelton & Valentine, 2003). In essence, these approaches distinguish between absence from conventional or recognised spaces of participation and generalised 'across the board' apathy and passivity. The consequences of this ever-widening definition of the political are complex, and will be discussed in the next chapter. This chapter seeks simply to present the ways in which my interviewees "operated" (de Certeau, et al., 1980) within, and did not merely passively 'use' health services, by attending to ostensibly mundane everyday experiences. This perspective allows us not merely to defend young people within the political realm (by pointing to alienation, not apathy (Sloam, 2007)), but to turn the question back: why do we expect young people to be involved in influencing the NHS?

INTRODUCTION

This thesis places at its centre the way in which ‘public involvement’, the particular vision of citizen participation dominant in UK health-care since the 1990s, has been practised in one Community Health Partnership in Scotland. This, then, is the story of Rivermouth’s enacted (or “materialised” (Dubois, 2010)) version of a policy agenda already, in its Scottish-ness, at one remove from the original inspiration of UK public involvement policy. Although, as Barnes (2007, p. 241) has identified “it is increasingly difficult to make a clear distinction between officially sponsored participation and autonomous action”, for the purposes of research it has been crucial to be clear that the object of my study is not ‘involvement’ as spontaneous phenomenon but the actions which stem from Cruikshank’s (1999) ‘will to empower’, in which both the do-ers and the doings are centre stage. Accordingly, this is a study of how one state institution ‘does’ participation (the “macro-political uptake of mini-publics” (Goodin & Dryzek, 2006)) drawing on the accounts given by a range of actors, including a sample of ‘non-participants’, along with analysis of documents and observation. As an interpretive study, it seeks to consider this topic from multiple standpoints, and questions the extent to which the object of the study has shared meaning from these different perspectives. I propose that Rivermouth exemplifies public involvement as a practice of government, as much as a practice of bottom-up participation. This supplements a trend in UK and international literature (Cooke & Kothari, 2001; Cruikshank, 1999) which point to the potential for governmentality or control within “Empowerment Talk” (Eliasoph, 2011). However, my research suggests that staff can by-and-large be understood not as manipulative controllers, but as puzzled facilitators, muddling through (Lindblom, 1979) in a policy context marked by contradictory pressures and sedimented layers of demands. Relatedly, I try to problematise the implicit vision of ‘the public’ as clearly defined entity impatiently awaiting empowerment. This brings members of the public, and thus the will to be empowered (or lack thereof), on stage also.

In this chapter I will draw together my answers to the research questions posed in chapter 3, necessitating reflection on the personal shifts in my own 'standpoint' as a researcher during this project. I then discuss the implications of these findings for our understanding of public involvement in health. Finally, I move beyond the specific context of health services to consider the theoretical implications of this case study as an example of broader trends towards state-initiated citizen participation. In so doing I aim to demonstrate the particular value of an interpretive approach, and specifically the manner in which careful attention to micro-level processes can offer insights into some of the bigger questions political science currently faces.

ANSWERING MY RESEARCH QUESTIONS

In chapter 3 I introduced the four research questions which structured my research. As well as offering answers to these questions, my research revealed and unsettled some of the assumptions on which they were predicated. In this section I discuss my answers to each question in turn.

1. How is public involvement operating at the local level in Scotland?

My first research question sought a brief account of the implementation of public involvement at the local level, as a starting point from which to understand the experiences of young adults. Initially envisaged as a minor, contextual part of the project, this became far more significant as research progressed. Firstly, chapter 2 reviewed academic literature on public involvement in health. This envisaged public involvement as a topic caught between multiple literatures, and uneasily located at the intersection of multiple trends. The academic literature has responded by 'conceptualising' public involvement through a series of abstract typologies. My review demonstrates that over time these typologies have become more simple and less ambitious. In an attempt to deal with the under-acknowledged disagreement about the meaning and goals of public involvement, I propose instead that we conceive of it as a topic for study. Seeing public involvement as something that people and organisations 'do' (or perform) rather than as a goal (whether consumeristic, democratic, or

emancipatory) renders it manageable and questionable as a research topic. Questioning the extent to which 'public involvement' has shared meaning likewise 'fits' with contemporary accounts of policy which acknowledge the complexity of the policy world, and put the 'policy cycle' in its place as heuristic device, not depiction of reality (Colebatch, 2005). By tracing even the very recent history of public involvement in the Scottish NHS it is possible to see the sedimentation of policy in this area. Shifts in emphasis and understanding of the involvement project are discernable, but subtle. Even *Better Health, Better Care*, which proclaims the novel vision of a mutual NHS, makes no clear break with the past of public involvement policy. Instead, initiatives and terminology are layered upon one another, unevenly supplementing the existing policy. It seems likely that this characteristic of policy development is particularly marked in the area of public involvement, where "warmly persuasive word[s]" (R. Williams, 1976, p. 76) prove difficult to pin down or refute.

In chapter 4 I characterised public involvement practice in Rivermouth – how the policy is enacted – as an assemblage. This points to the contingent nature of how staff muddle through in the absence of a clear guide from policy. It also, crucially, allows us to appreciate involvement as the cumulative activities of individuals, organisations, and brief coalitions of them, alongside non-human 'actors' such as project reports and the Involving People database. Initial intentions of 'mapping' public involvement implied a much more stable and distinctive set of actors and locations than I could discern. Existing organisational charts produced by staff members either sprawled across multiple pages, with every unit which had any involvement function listed, or pointed simply to Jennifer, the CHP's Patient Focus Public Involvement 'lead'. Within the assemblage I portrayed, distinctive groupings pursued approaches to involvement which, although rarely conflicting, could be identified as varieties. While these strands of activity were all, in their own way, 'involvement', it was difficult to define the boundaries where involvement stopped. In Rivermouth, a shift in national policy emphasis was recognised by those staff who came into contact with policy documents, but had yet to filter through into major shifts in practice. Practitioners, in particular the health improvement staff who conducted outreach activities, took their lead more from initiatives such as Walk the Talk (developed by the national organisation NHS Health Scotland), voluntary sector organisations such as YoungScot or international bodies like the World Health Organisation. These activities were embedded in their professional

practice: health improvement staff described a participatory approach as simply how they work. Projects could be usefully enlisted in the involvement assemblage (when I asked questions, or when staff were required to report to the Health Board, the Scottish Health Council or the Scottish Government on public involvement), but did not originate within it. This enlisting was enabled by amorphous understandings of involvement. For example, convening focus groups to ask young 'hard-to-reach' people about their health (to inform service provision) was seen as serving policy goals which are couched very differently in terms of citizen co-ownership of services. My research highlights that, in addition to the individuals who drive an agenda forward passionately, there are those who, like Jennifer, have responsibility for an agenda added into their existing role and do their best to deal with that alongside the other demands on their time, or who, like Donna, find their everyday standard practice suddenly relabelled and co-opted for an agenda it had little to do with. This is fairly distinct from the narratives of failure which preoccupy many existing assessments of public involvement practice, where staff are identified as unwilling to cede control, or keen to manipulate involvement for their own ends (Harrison & Mort, 1998).

An interpretive assessment of the 'implementation' of involvement also required a full account of the perspectives of public participants within the assemblage, specifically those engaged with the Public Partnership Forum. Based on observing the PPF for a year, and interviewing members past and present, chapter 5 describes PPF members, and reports their perspectives on their role, within the context of my observations about meetings. The PPF was designed as a network-style organisation, but in practice functioned in a very traditional hierarchical style, with formal, minuted meetings. Some of the members had been involved since the days of the Local Health Council, and some of the style of the organisation had been imported. Newer members expressed confusion about the 'point' of these meetings, but their existence (the gathering of these people around a table with an agenda and a note-taker) was the very back-bone of the PPF, without which it could hardly be said to exist. As a statutorily mandated organisation, it *had* to exist. Within the PPF I once again identified different 'modes' of involvement, but this time from the perspective of the public. The likely corollary to the "will to empower" (Cruikshank, 1999) – the will to be empowered – was variably present and many members understood themselves primarily as volunteers for the greater good, reflecting Simmons and Birchall's (2005, p. 270) characterisation of the 'foot soldiers' of

participation. This 'mode' of membership sought not power, but to serve. Others adopted an expert orientation, in which they understood their role as providing relatively technical advice to make things unequivocally 'better'. While individuals operating within this mode of membership wanted to be heard, this demand was rooted in the quality of the expertise being offered, and not in public legitimacy. Only one member was seen to understand his role as advocacy or representation of a specific cause, and even here he preferred the language of 'consultancy' to that of activism. Far from using the PPF as a "technology of legitimation" (Harrison & Mort, 1998), there was evidence that staff tried to support and even 'empower' the PPF, but that the members preferred to respond to direction from within the CHP.

2. How are young adults using the public involvement mechanisms available to them?
3. What are the reasons for limited or non-use of public involvement mechanisms by young adults?

My remaining research questions explored the role of young people within public involvement mechanisms, assuming their absence. Having explored the assemblage of public involvement, I was aware that 'youth' perspectives were sought via existing representative structures (Members of the Scottish Youth Parliament) and through small groups of school-age people engaged with health improvement activities. None of my interviewees were familiar with these avenues, although several reported hearing about MSYPs when they were at school. My research questions asked why young people were absent, and what the implications of absence were. While some young people's perspectives were heard within public involvement mechanisms, my interviewees were not involved, primarily because they had not heard of them. This implies a failure of communication on the part of the CHP, but because my interviewees were not interested in being involved even after having the mechanisms explained, it could also be seen as a sensible use of communications resources. This resonates with the distinction between the communication duties of Returning Officers for the opportunity to vote, and between private sector PR companies who would instead focus communication efforts on those most likely to sign up. It points to the way in which technologies of engagement – the ways organisations get people to engage with them – can be unsuited to public contexts where questions of equity demand a more proactive approach.

Overwhelmingly, this section of the interviews revealed the depth of “unshared meanings” (Patterson, 2000) between my own, policy-oriented frames of reference and those of my interviewees.

Seeking to better understand the polite but profound lack of interest in formal mechanisms of public involvement or political action, I resorted to asking about my interviewees’ use of NHS services. In retrospect, the fact that a conversation about public involvement mechanisms could proceed with so little reference to one’s own health is telling. I heard pragmatic accounts that a patient survey (such as that recently introduced by the Scottish Government) would likely classify as satisfaction. My interviewees had relatively little experience with the NHS, and their needs had, as far as they were aware, mostly been met. However, echoing findings in other studies which use qualitative methods to interrogate ‘patient satisfaction’ (Dougall, Russell, Rubin, & Ling, 2000), as the conversation went on several interviewees began to reveal ‘troubles’, or at least, unresolved concerns. What was remarkable about these tales was the lack of resort to public measures, and the variety and creativity of tactics used to ‘work around’ problems. Drawing on Scott’s (1990) theory of resistance in non-democratic contexts, but particularly on de Certeau’s (1984) philosophical depiction of the ‘ruses’ available to individual ‘consumers’ in systems of tight discipline, I began to recognise my interviewees’ non-resort to public action as a manifestation of agency. The ‘absence’ or ‘non-participation’ of young adults which had fitted so easily with existing theories of apathy became problematic, and interesting: “I realised that it couldn’t be true that nothing was happening. Something is always happening, it just doesn’t seem worth remarking on” (Becker, 1998, p. 96).

4. What are the implications of limited or non-use of public involvement mechanisms by young adults?

In my last research question I had half-developed hopes of exposing a bias towards the elderly in local NHS decision-making. This works on the assumption that ‘the usual suspects’ (white, middle class, but most pertinently for this study, exclusively retired) exert some degree of influence or power through their involvement activities. In practice, I found that the formal mechanisms of involvement are but one input into the

CHP. The PPF makes an effort to hear from staff who have done work with different groups of service users. Staff advocate for different perspectives, and concerns about 'equality' – interpreted as about fixed statutorily defined groups – were seen to be ever-present. Secondly, the 'decision-making' process in the CHP was heavily constrained by Board level decisions, and indeed Government agendas. While CHP committee minutes showed occasional decision points, these were rarely controversial within the committee. These processes appeared managerial and technical, not political. Premises closures were the exception to this, and they were recognised as contentious in both the CHP and the PPF. In sum, this question, as originally conceived, misunderstood the nature of local health service decision-making. However, it can also be interpreted more broadly, allowing for other answers. 'What are the implications of the absence of young adults?' can be understood as 'what does this mean'? Or, more bluntly, 'so what'? This is the question this chapter seeks to address.

The process of thinking back to these research questions, and thinking critically about them, sheds new light on this project. In retrospect, I can understand that those questions emerged and were articulated within the assumptive worlds of public involvement policy (the "mental models" that "provide both an interpretation of the environment and a prescription as to how that environment should be structured" (Denzau & North, 1994)). They are questions that could be associated with a research project similar to those Donna was conducting in Rivermouth (except that instead of asking how public involvement had been implemented, Donna would have drawn on existing organisational accounts of this in an introductory section to the report). They are filled with assumptions (public involvement is a clear mandate and will be implemented, young people are part of something called the public, young people are not involved) which identify me as committed to the idea of public involvement (a believer in public involvement) with concerns about its present conduct. I sought – without consciously realising it – to unpick particular puzzles and allow practitioners to do public involvement 'better'. While for those concerned with public involvement in Scotland there is some intrinsic interest in the findings summarised above – in the picture of one instance of public involvement it draws – connections can be drawn both with literatures of public involvement in health and with broader issues of governance and participation in developed liberal democracies. In the next sections I will discuss some of these broader 'implications', before, in the context of these connections, moving

to the more practical business of recommendations for policy and practice in my conclusion.

ANSWERING BIGGER QUESTIONS

The chapter structure for this thesis separates my findings into three perspectives – one organisational, one from the perspective of participants, and one from ‘outside’ – but I understand them as contributing to a broader picture of public involvement. An interpretive approach allows us to understand these three groups of perspectives (for within each chapter there are a range of perspectives) as equally valid. Interpretive researchers engage with ‘postmodern pluralism’ to argue for the presence, and validity of ‘local knowledges’ (Yanow, 1987). Although interpretive researchers have articulated and labelled this approach in an effective manner, it has a range of theoretical antecedents, including phenomenology, hermeneutics, ethnomethodology, and symbolic interactionism (Yanow, 2006b). These theories have been more fully developed in sociology than in political science, and classic texts of qualitative sociology have repeatedly proved useful in this project. One example is Wiseman’s (1979) *Stations of the Lost*. Drawing on symbolic interactionism, this account of ‘Skid Row’ is told from two perspectives: that of the homeless alcoholics who populate the institutions of Skid Row, and of the ‘agents of social control’ who staff them. Each chapter offers two distinct accounts of the same issue:

“No attempt is made to reconcile these two points of view nor to present any sort of objective ‘reality’. Between the protagonists no such reconciliation of viewpoint has occurred, thus, I cannot presume to know what would constitute a common meeting ground.” (J. P. Wiseman, 1979, p. xviii)

Wiseman refuses to adjudicate by identifying one standpoint as more ‘true’. The juxtaposition of these two accounts within the book acts as a reconciliation of sorts, in that they remain separate but comprehensible. The meanings of various structures and behaviours are different for service user and staff, but both are opened up to the reader’s understanding. Thus where an alcoholic points to the ‘coldness’ or ‘heartlessness’ of staff, Wiseman (1979) offers a staff member’s account of the repeated disappointments of seeing clients relapse into drunkenness. While this might not

reconcile the two perspectives by valuing one above the other, it allows us to understand how both can reasonably occur. In my research, an interpretive approach allowed me to understand variation in the accounts of public involvement given by different actors as interesting and valuable, not as a contradiction to be ironed out through analysis.

Taken as a whole, then, what can my case study of Rivermouth tell us about public involvement as currently practised in Scotland's increasingly distinctive National Health Services? My literature review raised two central puzzles, prompting me to question the presence of any shared meaning around either the 'what' and the 'who' of public involvement in the NHS.

WHAT IS INVOLVEMENT?

What was public involvement in Rivermouth, or what did it consist of? Drawing together chapters 4, 5 and 6, I can expand the concept of assemblage outlined as a characterisation of the organisational perspective. As well as the organisations, staff, documents and technologies which comprised how the CHP 'did' involvement, both PPF members, and the fabled, unreachable or unreached imaginary of young adults (as well as the representations of young people's views present in meetings and documents) were part of this assemblage. My young adult interviewees were present within the spectre of 'the public' raised to justify or dismiss particular perspectives, and in the enthusiasm of various people for the outreach work Donna was doing. They were also present, as imagined, in the occasional cynicism of PPF members about the wider public. From the perspective of my young adult interviewees, public involvement was not a meaningful part of their map of the NHS. For me as analyst to insert boxes for public involvement on an organisational chart would give public involvement an authoritative existence which was, in the field, much less evident. Again, the concept of assemblage allows me to illustrate the contingency of these practices. Encountering the NHS at the 'wrong' moment, or from the perspective of someone seen as a 'difficult' patient, it would be entirely reasonable to conclude that public involvement was absent in Rivermouth.

However, activities which local actors described as involvement were ongoing. Grounding 'involvement' firmly in a set of actors and their actions allows us to escape unhelpful typologies which (as I argued in chapter 1) have come to dominate the public involvement literature: "it is best to begin not with definitions but with examples, with exemplary instances that almost everyone is likely to accept as instances of practices" (B. Barnes, 2001, p. 18). Fundamentally, these typologies lack awareness of practice, consisting mostly of summative assessments (evaluations) of activity. In Rivermouth the practices of involvement included: scheduling and holding meetings; producing papers for the PPF in an NHS document template; reading papers and noting possible comments or queries to raise in the meeting; producing promotional flyers, coasters and pens to encourage people to get involved; suggesting outreach projects for 'hard-to-reach' groups (then meeting other staff to discuss or plan them); writing strategies and self-assessment reports; conducting surveys of current service users; submitting summaries of projects for the database; producing, filling in and collating evaluation forms for presentations at PPF meetings. These mundane actions were what public involvement consisted in, because it was at heart an organisational process. From this perspective, the descriptor 'involvement' – bland and non-committal – seems entirely appropriate.

Chapter 4 revealed the ways in which public involvement was embedded into Rivermouth CHP as a set of administrative processes. The nature of NHS decision-making at local level appeared particularly remote from the realm of private lives. Despite claims of a modern network-based organisation (Woods & Carter, 2003) I would argue that the Scottish NHS remains closer to a traditional hierarchy. The committee meetings into which 'public' views were fed in Rivermouth rarely include recognisable decision points. Any given personal problem – for example Lisa struggling to be taken seriously by her GP – was nested in training, guidelines and rules from central Government, (translated down by NHSScotland, Boards and CHPs), from the Scottish Implementation Guidelines Network, from the General Medical Council. While this complexity is not unique, the dearth of political accountability (as distinguished from managerial accountability (Day & Klein, 1987) of which there was no shortage) made it near impossible to locate a 'way in' to influence the micro-level problems that my interviewees experienced. As a result, public involvement either operated at the level of strategic organisational decisions, or had to be translated up to this level by staff.

Whether this account of Rivermouth's assemblage of public involvement reveals anything about the possibility or nature of a Scottish model of public involvement (what public involvement 'is' in a devolved Scotland), is less clear. Certain features are encouraged by Scottish policy, but very little of their content is prescribed. For example, PPFs are a statutory requirement for CHPs, but their form can and does vary significantly across Scotland (FMR Research, 2008). The pressure for CHPs to demonstrate the involvement of a wider spectrum of society, and particularly hard-to-reach groups, comes in part from the Scottish Health Council's priorities (Scottish Health Council, 2010), locally evident in annual self-assessments, but how this is achieved might look very different in different contexts. Rather than attempt to assess whether Scotland's national public involvement policy is, for example, democratic, consumerist or emancipatory I see my key contribution as directing attention to the diversity of forms within one small locale. Understanding public involvement practice as an assemblage highlights the contingency of outcomes, and the extent to which particular individuals can transform what public involvement 'is' without particularly troubling existing structures. It is difficult to make overall assessments of policy for participation, as so much is dependent on the conduct of both staff and the public at the micro-level. This is not to advocate for a focus on techniques, handbooks and 'toolkits' of public involvement, which Barnes, Newman and Sullivan (2007, p. 201) rightly critique as contributing to the depoliticisation of the phenomenon. Instead rich, qualitative accounts of 'what happens' in particular contexts can be developed into knowledge of what Wagenaar (2007, p. 31) calls the "software" of participatory projects.

WHO IS THE PUBLIC?

Pressures for diversity and ill-defined concerns about representation have plagued the history of public involvement mechanisms in the UK NHS. In his 'sociological review' of citizen participation in health, Contandriopoulos (2004, p. 328) considers this issue as the defining dynamic of this realm of action: "The efficacy of public participation, a particular type of political action, characterised by its reliance on weak and informal representation mechanisms, will depend upon the ability of the – often self-designated – public's representatives to appear as a legitimate spokesperson for the group".

Technical solutions to the problem of representativeness have been proposed. Goodin

and Dryzek argue for deliberative mini-publics, with “some claim to representativeness” (Goodin & Dryzek, 2006, p. 221). Warren (2009a, p. 8) similarly proposes random selection of citizens for large-scale deliberative projects “delinked from both the strategic elements of electoral politics, and the unfocused elements of broad publics”. While a ‘designed mini-public’ might achieve a degree of descriptive representation through strict application of quotas, or a statistically sound sample through random sampling, these techniques essentially overestimate the extent to which ‘representation’ is a straightforward goal which can be ‘achieved’, rather than a multi-faceted process (Newman & Clarke, 2009, p. 140; Pitkin, 1967).

Newman and Clarke raise concerns about an emphasis on representation (and likewise the related idea of authenticity):

“Representation ... rests on a narrow view of politics and of identity. It essentialises identity itself, inviting people to ‘stand for’ specific categories: the young or old, black or white, male or female populations, without taking any account of the dynamic relationships between the multiple dimensions of personhood. In the search for representativeness... This process of categorisation [by public officials] does not reflect a pre-given public, but is constitutive of it” (Newman & Clarke, 2009, p. 141).

In the specific field of health, ‘the public’ is created (or constituted) as a unified category from a population which could instead for example, spilt into the profoundly different constituencies of patients and tax-payers (and one need only glance at the positions of the Tax Payers’ Alliance and the Patients Association to see the difference). This odd coalition helpfully slots into representations of the existing NHS power struggles between managers, health professionals and the Government (Klein, 2010). However, like all of these categories, but more so given its lack of professional bodies, trade unions or institutional training, ‘the public’ does not exist as a single entity, and never has. Given increasing debates about the political viability of a NHS with increasing awareness of the lifestyle factors influencing our health, it seems unlikely that the NHS’s public will become a more coherent entity. Thus, when I presented information from my interviews with young adults to the PPF, including the story of Lisa being removed from a practice list because of alleged missed appointments, it should not have been surprising that members’ first reaction was that missed appointments are a major problem for GP practices in Rivermouth. Members were not ‘the public’ (in that their loyalties were not

uncritically to any individual within it) and crucially, the non-directive, make-of-this-what-you-will style of the PPF had not turned them into representatives of the public.

The most comprehensive consideration of this issue as regards public involvement in health comes from Martin (2008a, 2008b) . He identifies the contradictory policy-level demands for participants to be simultaneously 'ordinary' (in the sense of descriptive representation) and 'extraordinary' (in terms of the tasks they are required to perform 'effectively'). In other co-authored work he describes this as a 'catch-22' for participants to negotiate (Learmonth, et al., 2009). My findings support those of Martin in that both administrators and participants in Rivermouth recognise, and worry about, the demands of representation. This is evident both in James's muted frustration about public apathy in a discussion of poor turnout at public events and in Thomas's suggestion that the Forum should conduct small research exercises. However, my analysis differs from Martin in that his recommendation is for groups to be given more space: "if bodies ... are to do more than provide unthreatening, homogenous and tokenistic public perspectives, they need to be given space and time to pursue their own agendas" (Learmonth, et al., 2009, p. 114). The authors argue that more 'ordinary' people will take part if participatory bodies are not required to contribute to the pre-defined decision-making processes of health care organisations.

This resonates with Bang's (2005) influential 'everyday makers and expert citizens' critique. He contrasts the professionalised behaviour of those citizens who regularly engage with local governance with 'everyday makers' who:

"consider knowing as doing, refusing to take on a professional, full-time or strategic citizen identity. They want to do things in their own way, right where they are, when they have the time or feel like it. Their engagement is more 'on and off' and 'hit and run' than that of the expert activist. Everyday makers do not shy away from being enrolled in strategic civil governance projects, but do so only if they give them the opportunity to also pursue their own 'small' tactics and exercise their creative capacities as 'ordinary' citizens" (Bang, 2005, p. 162)

Bang's definition of these tactics remains in the political realm – that of strategic civil governance projects – and he does not attend to the creative potential of citizen's

interactions with public services. By this critique of professionalised participation processes, as with Learmonth, Martin, and Warwick's (2009) proposals, creating more fluid, bottom-up structures should engage the elusive 'ordinary' citizens who have hitherto stayed outside such processes. I find such suggestions unconvincing.

The more practice-focused account of participation which I have tried to offer in Rivermouth considers the issue in terms of work, not power. Where Learmonth, Martin, and Warwick (2009) (and implicitly Bang (2005)) see unstructured space for participants to assert their own agendas and priorities, I see additional work for participants in forming and articulating those priorities with nothing to assert themselves against. In a very different context, Eliasoph's exhaustive ethnographic research on what she terms 'Empowerment Projects' in American cities describes scenarios where "Organisers did not want to stifle volunteers' creativity so they repeated, in words that varied slightly in one meeting to the next, that their organisations were 'open and undefined, up to you to decide 'whatever'" (Eliasoph, 2011, p. xvi) . Her book is full of poignant, funny tales of purposeless meetings where organisers try to prompt activity from the young people in attendance without seeming to control or restrict the options. In these projects – as in the type of bodies preferred by Learmonth, Martin and Warwick (2009) – the focus on enough people 'being there' usurps the purpose or outcomes of any given activity. Their presence becomes the outcome. The result is a nebulous realm of meetings and activities: "where there are no apparent limits, the only taboo was against taboos; the only stated rule was to declare that there is no rule" (Eliasoph, 2011, p. 232). Organisers who have to demonstrate 'bodies in rooms' to their funders resort to offering junk food or certification of achievement for hours spent in projects to keep citizens coming to something where the 'being there' is in itself the output. In Rivermouth PPF Jennifer repeatedly tried to encourage members to initiate, or to innovate, but new members coming in asked not 'how I can achieve the changes I want to see?', but, as Margaret repeatedly asked me, 'what is the point of all this activity?' Removing the structures and asking less of public involvement mechanisms seems unlikely to increase the diversity of attendees in itself.

Crucially, though, my findings in Rivermouth suggest that while there are reasons to be concerned that particular viewpoints and experiences were not heard within NHS

decision-making, the concerns expressed in parliamentary reports that public involvement empowers only middle class, middle-aged white people were not valid in this case (House of Commons - Health Committee, 2007). Not, sadly, because I had complete confidence in the way the local assemblage incorporated outreach projects which did reach more marginalised sections of the population, but because the PPF members made no perceptible gains in influence through their participation. Rather, they did work (a tremendous amount of it). Furthermore, and most puzzlingly for those, like me, entrenched in a political frame, they were mostly quite happy about this.

MOVING BEYOND

In addition to specific learning around the way that the NHS 'does' public involvement, and the way that academia has critiqued it, I believe that public involvement can be fruitfully understood as one instance of a broader trend towards 'empowerment' and 'participation' of citizens. Warren (2009a) identifies the macro-level pressures which prompt a growth in state-initiated citizen participation: administrative contexts have expanded with the greater complexity of the state; Westminster systems concentrate power but fail to communicate preferences before decisions are made; citizens are increasingly educated and assertive. These factors lead to the particular growth of citizen participation initiatives, but these have taken place primarily within public administration, and not within the political system: "The frameworks of engagement usually have administrative rather than 'political' origins. And administrators are typically seeking citizen input rather than citizen empowerment in decision-making" (Warren, 2009a, p. 18). This section draws upon the insights of my research in Rivermouth as a case study for 'participation' in administrative contexts as a broader trend. It reuses the distinction discussed in chapter 2 between public involvement as citizen participation and as governmental action. Firstly, I discuss the participatory realm by reflecting on what I characterise as everyday politics in the welfare state. With this realm of everyday politics as a lens, I turn to consider participation as a chimerical project for government, reflecting on the insatiable tendencies of participatory activities, and the way in which this limits their capacity to transform governance. Throughout both I emphasise citizen participation as something that is done by the state, and, to a variable degree, by its citizens.

EVERYDAY POLITICS IN THE WELFARE STATE

Traditionally the territory of sociology (Goffman, 1956), concepts of the 'everyday' are of growing interest in political science (Soss, 2000) and in studies of public policy (Dubois, 2010). Conventional accounts of state-initiated citizen participation have centred around the "invited spaces" (Gaventa, 2006) in which citizens have been permitted to express their views, or formalised user groups who lobby within them (M. Barnes, et al., 2007). Taking seriously those who are absent from these spaces may require us to look beyond them. Recent work on young people's political participation has argued that "the mainstream literature has tended to operate with a narrow imposed conception of the political... It therefore fails to engage with how young people themselves conceive of the political and does not attempt to investigate their political imaginaries" (Marsh, et al., 2007, p. 4). Findings from this and similar research have pointed to a wider spectrum of 'political' activity: "most of our respondents lived politics; they were consistently faced with the consequences of politics and often recognised these experiences as 'political'... while they often recognised politics affected them, they felt they had no chance of influencing it" (Marsh, et al., 2007, p. 211). Given evidence of alienation from formal politics, other work looks for channels through which youth identities are expressed – such as specific music cultures – and understand them as political, although they "[do] not need to engage with [the institutions of governance] since [their] agenda is pleasure and survival" (Riley, et al., 2010). In their desire to 'read' politics into young people's lives, such researchers abandon the requirement for politics to be a process of negotiation in the pursuit of change (Warren, 1996).

Youth non-participation has preoccupied academic study of politics for some time, and I was similarly puzzled by the reasons why none of the negative encounters my young adult interviewees recounted had translated into action through the system. However, focusing on 'what they *do* do' helped me to understand the progression from individual patient to (public) participant as a complicated journey. For heuristic purposes, I argue that there are three stages in the mobilisation of a negative experience into action (or as Scambler and Britten (2001), drawing on Habermas (1987), would describe it, the translation of events in the patient's lifeworld into action to try to influence the system).

Firstly, the individual has to recognise the fact of a problem. As discussed in chapter 6, while a few interviewees were quick to describe problems, others were tentative in recounting them, and others yet seemed to surprise themselves with previously unarticulated “troubles” (Schegloff, 2005). The occasional nature of service use, and the non-life-threatening nature of most of the health problems described, meant that it was often possible not to dwell on a negative incident. Secondly, in our interviews, or in the complaints system, or even, if they so chose, through the Public Partnership Forum, the potential existed for my interviewees to recognise troubling experiences with the NHS as injustices, where “what had been accepted as personal trouble comes to be seen as an actionable public issue, a matter of justice” (Pitkin, 1981, pp. 347-348). In politicising or publicising something in our private lives we are, Pitkin argues, asserting its actionability. This entails feeling not just aggrieved, but confident that one’s own actions were appropriate, and that we are not ourselves to blame.

However, and crucially, my research seeks to illuminate the presence of a third decision point, between taking the public route of action, or instead keeping the issue private (in Pitkin’s (1981) sense that it is not recognised as collectively actionable). The available public routes in Rivermouth included, as well as the prescribed routes of the PPF and formal complaints mechanisms, the local newspapers, who would put ‘scandals’ on the front page. Within these public measures, engaging with the PPF is by far the most effortful and insider tactic. By contrast, the other two public measures are more outsider tactics. They include a degree of abrogation – in the absence of understanding how one might change an institution, simply holding up an incident as beyond acceptability, for some other process (one orderly, quiet and formalised, the other loud, angry, unpredictable) to adjudicate. However, each of these are better suited to a dramatic tale of injury and outrage, than, for example, the series of small indignities which Lisa described to me. The neglect of the presence of quiet, privatised avenues of action within the discourse of public involvement is a key finding of this thesis. It emphasises that, having recognised ‘trouble’ in an interaction with the state, there are two further moments of transition: a step from the personal to the political (a justice claim, as Pitkin would have it) and a second transition from private to public action.

By listening to the way that my young adult interviewees talked about using health services, I identify several of these quiet, privatised tactics. I argue that despite these characteristics they can be read as political in two distinct ways. Firstly, and most extreme, it is possible to understand silent inaction – or avoidance – in response to an opportunity to engage, as political. Jaworski (1993, p. 5) uses the example of a student in class who, when asked his views on a poem, says nothing. The next student replies “I agree with him”. It is possible to understand low response rates to my request for interviewees, and the anxious “I don’t know” of pilot interviews as part of the same phenomenon as the struggle to get young people particularly, but members of the public generally, to participate in public involvement. Low awareness of these opportunities, and confusion about what they are, clearly contribute to unwillingness to take part. However, accounts of ‘refusal’ of policy aims (Prior, 2009, p. 31) and ‘withdrawal’ from collaborative interventions (Sullivan, 2009, p. 49) illuminate the way that this can be understood as an active behaviour. Hirschman (1970) includes “separatism” in his modes of exit, which Patterson (2000, p. 689) describes as “a form of silent discourse that is so deviant and visible that it embodies implicit critique of the mainstream, coming ‘close’ to a form of voice”. The essential point here is that policies for collaborative or participatory governance are particularly easy to subvert. Where, for example, refusal to comply with a welfare regime requires a negative action, the inclusive, positive tone of opportunities to participate can be very easily unsettled by individuals simply going about their everyday business. While it is easy to understand this as apathy, it can also be understood as a very profound rejection of the opportunity.

A second approach, which I used extensively in chapter 6, is to understand use of public services, and the opportunities for everyday creativity therein (de Certeau, 1984), as (political) claim-making. This position draws on a tradition of research which investigates the welfare state as a site of politics (Piven & Cloward, 1972), and more recently on Soss’s (2000) monograph *Unwanted claims: the politics of participation in the US welfare system*. Soss draws on interviews with recipients of two types of benefit – a social assistance programme and a social insurance programme – and investigates the citizenship implications of the process of claiming.

“As a mode of political action, welfare claiming is distinguished by the fact that it allows citizens to gain a direct and personalised response from government. Welfare

bureaucracies are more accessible than most government institutions and offer citizens more immediate, targeted, and tangible remedies” (Soss, 2000, p. 59).

The parallels between this study and the claims my interviewees made by seeking NHS care are of great interest. It is not customary to understand going to the GP, calling NHS 24 or attending Accident and Emergency as claim-making. However, when my interviewees, most of whom were in relative good health, spoke about visiting the doctor, it revealed a process of decision-making, including multiple incidents when the problem was eventually deemed too trivial to proceed. Eventually making the telephone call was, like Soss’s respondents’ accounts of welfare claiming, a decision rooted in social expectations, norms and advice from friends and family. Attending to this decision-making “recovers the agency of people who seek to mobilise their government’s welfare institutions” (Soss, 2000, p. 59). Particularly in cases where interviewees quietly persisted in seeking care for a medical problem which they had been told was simply a by-product of their lifestyles, this agency is brave and significant. Recognising policy pressures for ‘responsible’ service use – particularly around ‘inappropriate’ use of Accident and Emergency but also present in the Rivermouth system of emergency GP appointments – helps us to appreciate the political dimensions of seeking care through the NHS.

Private tactics within public services (whether avoidance or everyday creativity) connect with broader literatures, almost invariably from marginalised positions of gender, ethnicity or social class, on the risks of ‘going public’, and the advantages of privacy and silence (Lorde, 1984; Patterson, 2000). Lorde (1984) writes that “the transformation of silence into language and action is an act of self-revelation, and that always seems fraught with danger”. There seems to be something particularly self-revelatory about going public with one’s experiences of ill-health and health services, as Cornwell’s well-known distinction between private and public accounts of experienced health suggests (Cornwell, 1984). Negative interactions with the NHS, those which made my interviewees feel small, or silly, or fat, impeded the development of their sense of legitimacy, leading them to “pick up messages that their problems are not public but private and of their own making” (Ingram & Schneider, 2007, p. 179). Both the articulation of a justice claim, and the decision to adopt ‘insider tactics’ required opening up one’s personal decisions and body up for public judgement. Warren (1996, p. 248),

reflecting on the gap between our easy evocations of a more democratic society and the likely consequences of it, describes politics as a realm of “extensive contestability”, and an inherently uncomfortable place. Latour argues that in most cases: “we don’t assemble because we agree, look alike, feel good, are socially compatible or wish to fuse together but because we are brought by divisive matters of concern into some neutral, isolated place in order to come to some sort of provisional makeshift (dis)agreement” (Latour, 2005, p. 13). Given the lack of sympathy expressed by PPF members when I presented some of my young adult interviewees’ problems to them, it was perfectly reasonable to fear the judgement of one’s fellow ‘public’ as much as of the medical establishment. There was, by contrast, safety in either refusing to state one’s personal ‘troubles’ as political issue, or in doing so but refusing to follow prescribed routes of redress.

There is also a degree of effort involved in ‘going’ public which is underestimated by commentators who assume that experiences are neatly translated into preferences. Mol makes this point about the different set of actions associated with patient choice: “if the ideal of patient choice is drawn into health care, it does not finally make space for a ‘self’ that was always there. Instead, something is being asked from us” (Mol, 2008, p. 79). While this argument against service user choice can be put to work in the recurring ‘choice versus voice’ debates of public policy (Greener, 2008), it is, to a significant extent, a defence of inaction (or at the very least a call to recognise the work involved in being active). Habermas’s (1987) theory of communicative action, relied upon in much analysis of participation and deliberation, has been criticised for operating with a naïve understanding of discourse: “To enter into a discourse is to enter the language practices that constitute the mental categories in use, and not merely to enter a conversation by opening one’s mouth” (Patterson, 2000, p. 697). Thus the mind-set associated with both voicing and choosing public services, the considered reflection upon one’s experiences and preferences required for both behaviours, can be seen as something to be entered into, and not an innate feature of most people’s lives. This resonates both with interviews where negative experiences were articulated late in the interview, after a more general discussion, and cases where interviewees were reluctant about or obstructive towards my attempts to ask them to reflect on their experiences.

Considering the avoidance or everyday creativity (de Certeau, 1984) of my interviewees as political is productive, but there also risks with such an approach. As I highlight above, my interviewees did not describe this realm of activity as political, and my questions about voting or community activism yielded no health-related political concerns. Marsh, Jones, and O'Toole (2007) found that their focus group participants held forceful, cynical views on conventional politics, and felt themselves excluded from it. It seems to me that this is a classic example of our research methods "encourag[ing] respondents to speak in uncharacteristically serious ways about issues that they usually treat flippantly, or ironically, or do not discuss at all" (Eliasoph, 1998, p. 19) Gathering a focus group of young people to talk about what politics means to them seems likely to produce some views on what politics means to those young people, regardless of whether it means anything to them in the rest of their lives. Buckingham makes a similar point about his own research findings: "what the data suggest is merely that, under certain circumstances, young people may be *capable* of engaging with broadly political issues at a relatively sophisticated level – not that they necessarily do so in other circumstances, or in their everyday interactions" (Buckingham, 2000, p. 203). I would argue that taking young people's expressed views seriously means not just retaining the distinction between how they choose to live and what we understand to be politics, but thinking through what it tells us about both their lifeworlds, and the systems within which they operate.

In the context of debates about child-centred and adult-centred accounts of politics, several authors have followed Buckingham in cautioning against collapsing the categories of 'the personal' and 'the political':

"Attending to children's voices, experiences, conducts, spaces and places – and in so doing foregrounding if not individuals *per se*, then certainly a micro-political arena of personal, intimate, highly embodied affairs – cannot in itself illuminate the tangled politics...that determine the childhoods 'made' by adults for the children within their societies" (Philo & Smith, 2003, p. 107).

Thus, while acknowledging the presence and validity of micro-political activity within my interviewee's lives and the (relatively) macro-political organisational processes happening within the CHP, the distinction between them (the gap which troubled me so much during fieldwork) should remain clear: "the personal can *become* political, but this

requires a fundamental shift in how issues are framed or defined” (Buckingham, 2000, p. 204).

I have tried to demonstrate the extent to which keeping one’s troubles private can be a reasonable path of action. This is a surprisingly radical step within the literature on citizen participation. Squires argues that Arendt and other civic republicans see privacy as “not a right or a privilege, it is an absence of publicness and a lack” (Squires, 1994, p. 389). Cruikshank asserts that

“Democratic participation and self-government are regarded as solutions to the lack of something; for example, a lack of power, of self-esteem, of coherent self-interest, or of political consciousness ... participatory democratic discourse is preoccupied with subjects who do not rebel against their own exploitation and inequality, who fail to act in their own interests, and who do not participate politically even though free to do so.” (Cruikshank, 1999, p. 3)

To point to the gap between the everyday creativity (de Certeau, 1984) of my young adult interviewees and the system which is meant to be creating opportunities for their views to be heard does not necessarily entail either that young people are deficient in not realising the politics of their lives, nor that the system should be transformed to work for/with/on individual, anecdotal experiences. It simply points out that repeated demands for the empowerment of the public within the welfare state underestimates the agency already at work. The sociology of health and illness has already moved from the notion of a powerless patient trapped within a web of social control (Parsons, 1951) to an often asymmetrical but nonetheless active engagement with the medical system (Friedson, 1980). The genuine desire of many policy-oriented researchers to promote a more empowering welfare state doubtless contributes to their lack of interest in existing tactics used by members of the public in their interactions with it. However, it also contributes to their/my difficulties in making sense of many citizens’ lack of interest in sitting on committees to influence the future of local services.

BETWEEN PRIVATE LIVES AND PUBLIC POLICY: PARTICIPATION AS CHIMERA

Barnes describes user involvement and public participation initiatives as “dialogue between private lives and public policy” (2004, p. 20). This definition has instinctive appeal, and offers a neat solution to the troubling ‘gap’ in my research project. Perhaps this, and not, as Contandriopoulos (2004) would have it, the weakness of representative structures, is the defining characteristic of this realm of activity. We can understand public involvement as a description of activities which bridge the divide between personal (private) lives and the political (public) systems of the state. In the absence of political parties and the other conventional mechanisms of interest articulation in the political world, mechanisms are sought which somehow connect the everyday experiences and preferences of citizens to the process by which public services are governed. A similar aim drives the increasing interest in health services research and policy in the use of ‘patient stories’ (Patient Opinion, 2011; The King’s Fund, 2011; The Scottish Government, 2011).

However as Hoppe (2011, p. 163) suggests, the ambitions associated with more participatory styles of governance are rarely judged to be met in practice: “[L]istening to citizens’ and administrators’ stories about deliberative-participatory policy making, there are serious concerns about an emerging gap between the rhetoric of hoped-for or taken-for-granted benefits and their materialisation in reality”. This gap, the second discussed in this thesis, is variously attributed to failures of practice, to misjudged expectations from policy, or, in some quarters, to the dominance of ‘usual suspect’ participants. This section will argue instead that the gap between expectation and practice can be attributed to the inherently chimerical nature of ‘citizen participation’ initiatives. By chimerical I intend to suggest not that participation is a fire-breathing female monster with a lion’s head, goat’s body and serpent’s tail, but that participatory projects have at their core an unrealisable vision. This, it seems to me, is not inherent to theories of whole-system participatory democracy, but is particular to the technologies of government which attempt to ‘do’ (to perform, to enact, to assemble) projects of participation within the realm of public administration. This assertion links with my

characterisation of the term 'public involvement' as an empty signifier which masks different motivations while holding out the promise of "unachievable fullness" (Laclau, 2005, pp. 70-71).

The range of potential justifications for participatory projects – neatly summarised by Harrison, Dowsell, and Milewa (2002) and rephrased in this thesis as the democratic, the consumerist and the emancipatory – are a key source of this instability. While for some authors participation in the public services is the answer to each of these three challenges – simultaneously enhancing democratic equality, improving the service experience of individuals and combating the exclusion of marginalised groups – I suggest that it is instead constituted as an amorphous project which cannot satisfy these multiple goals. Newman and Clarke (2009, p. 180) argue "strategies for remaking the public in governable form have no singular force or logic, nor any guaranteed results". This builds on Sharma's (2008) account of the riskiness of empowerment projects. The instability of the multiple logics at play when participation is 'done' within the administrative context of public services – where guaranteed results are always preferred – leads to the lingering sense of dissatisfaction that seems to pervade both practice and analysis of participation.

More specifically, one chimerical feature of participatory projects is that on a very practical level they lack end-points at which success can be judged. Efforts to 'evaluate' the PPF in Rivermouth, along with outreach projects, demonstrate the difficulty of proving that participation has met any of its headline goals. For many advocates of participation, individual projects are merely one opportunity for 'the public' to get involved: Lowndes, Pratchett, and Stoker (2006, p. 283) argue that "in a democratic system the participation of all (all of the time) is not required; rather its defining characteristic is its openness to all". However, given awareness of the differential barriers to participation faced by groups within the population, specific projects seem often either to operate with or be held to more demanding criteria than contributing to 'openness to all'. In a sense, each project or mechanism is expected to operate as a synecdoche of the wider democratic system. However, as Yanow and Wilmott (1999, p. 452) observe in the different case of sampling for research, inevitable indeterminacy

stems from the “impossibility of knowing that all the actors and all their diverse concerns have been recognised and appreciated”.

The outcome of this indeterminacy is that participatory projects take on the character of a never-ending quest. One aspect of this is the persistent need to demonstrate engagement of the ‘hard-to-reach’, and the manner in which the definition of this group only shifts further away as specific groups are ‘reached’. Through the lens of my young adult interviewees’ perplexity at my suggestion that they ‘get involved’ with their local NHS, I would argue not only that Cruikshank (1999) is correct that participatory initiatives unilaterally define most of the population as ‘non-participants’, but that her argument can be pushed further. Participation within the public services not only reinterpreted my young adult interviewees as apathetic and disengaged, but NHS managers and staff as failed engagers. As an unbounded, amorphous entreaty, it could not be satisfied by any single ‘successful’ activity. Participation in this context is not merely difficult but insatiably unachievable. Crucially, I would argue that unacknowledged disagreement about the purposes of participation (between democrats, advocates of consumerism or emancipatory activists) means that the nature of the ‘achievement’ of participation would itself be disputed. Accordingly, modest achievements, enough to (literally) tick a box on impact assessments, while held on to, were tacitly known to be always inadequate. Participants, once ‘brought in from the cold’, were rapidly viewed with suspicion. Even those who could tick multiple boxes on a diversity monitoring form became the (sullied) ‘usual suspects’ once they had engaged with a process. Participation was never finished.

By arguing that participatory initiatives *cannot* satisfy the multiple goals contained within them, I offer an analysis which disputes the three dominant critiques of participation in the NHS identified in chapter 2, which locate blame for ‘failures’ at the level of policy, practitioners or ‘usual suspect’ participants. I will discuss the implications for policy further in chapter 8. By asserting that there is an inherent chimera within participatory initiatives, I deflect blame from the practitioners and staff who “muddle through” (Lindblom, 1979) on the ground. This is a challenge to the broad academic consensus that “it is difficult to escape from the conclusion that the aim of [staff challenges to the representativeness of participants] is to undermine users of

services” (Crawford, et al., 2002, p. 46). The argument that participatory initiatives are manipulated into “technologies of legitimation” (Harrison & Mort, 1998) by local health service managers is weakened when we acknowledge the size and complexity of the task facing these staff. Managers in the public sector serve many goals, and, as we have shown, those associated with ‘empowerment’ and even accountability to an ill-defined public are among the more amorphous. There are surely managers in the NHS who do adopt a tokenistic attitude to participation, but the argument that they subvert such activities from their true goals assumes a clearer set of goals than can be identified. Academic analyses of participatory initiatives have, as Contandriopoulos (2004) asserts, been complicit in sustaining a narrative of failure by operating with ill-defined yet demanding normative criteria. Secondly, persistent questions about the ‘legitimacy’ of participants assumes that public involvement offers individual power and influence to pursue agendas which are ‘unrepresentative’ of the wider public. If participation is not a transformative agenda but a distinct terrain of activities (indeed, of work and effort), then it is of far less interest to view suspiciously the individuals who ‘step up’. Understanding much of the work of participants as more akin to pushing a tea trolley around hospital wards than voting in an election transforms the concerns perennially expressed about representation within public involvement.

CONCLUSION

In order to do this research project I have had to distinguish between the values and ideals of democratic participation, and the actual technologies of participation used within the welfare state. Edmondson (1997, p. 3) argues that

“collective public participation should not be seen as a unitary phenomenon, inevitably praiseworthy. We need to know more about the generation and results of collective behaviour if we are to understand under what conditions it contributes to the intensification of democracy and when it might do the reverse.”

As analysts have become increasingly disillusioned with the practices they observe or hear about in state-initiated participatory projects, I would argue that the opposite of this has occurred, and we have become too ready to declare local failures in the enactment of what are “inevitably praiseworthy” intentions. The response has often been to look for ‘better’ participation. Thus Bang exhibits a welcome degree of

scepticism about the professionalised committees of strategic governance initiatives in Copenhagen, and looks instead for the 'hit-and-run' participants who appear on their own terms and disappear again. I fear that Bang's desire to contest the idealised view of professionalised NGO actors (which he identifies in statements such as "global civil society is a haven of difference and identity" (Keane, 2003, p. 208)) leads him simply to idealise an alternative group. After all, were expert citizens not once everyday makers? Do everyday makers never become expert citizens? How many times in a year does one need to attend an event to switch from one (praiseworthy) category to the other (blameworthy) one? There is a risk that this account of participation simply produces a new idealised category to contrast with the sullied 'usual suspects', and there is some evidence that 'everyday makers' are already seen, not as a novel type of participant, but simply as the residual category of people who do not participate (see for example Bochel, et al., 2008, p. 202).

In its characterisation of avoidance and everyday creativity (de Certeau, 1984) this thesis offers instead a very different account of action, which is intensely privatised, often silent, and sometimes fearful, embarrassed or scornful of the community in which it exists. My interviewees described *never* taking public action, but they were not inactive. Instead, I have tried to take my interviewees' tales of service use (and mis-use) at face value, respect their rejection of politics and participation, and value what I was told, independent of the policy frame which redefines these 'ordinary' lives as non-participation. In visual art, we are taught to attend to negative space (between objects in a still life, for example) in order to better depict the positive spaces (the objects themselves). This resonates with Jaworski's (1993) argument against treating silence as a category which does not communicate meaning. In this thesis, the inclusion of interviews with people not involved in influencing the NHS foregrounds the gaps and spaces around public involvement activity, exploring what people say goes on in the interstices of participation in the NHS. I understand this not merely as supplementing the picture of public involvement (like rendering the object at the centre of a still life more accurate) but as altering the picture that we see. Acknowledging the presence of privatised tactics of avoidance helps me to understand joining the Public Partnership Forum as, in the words of one pilot interviewee, "a really strange thing for me to do".

8. CONCLUSION: REFLECTIONS ON POLICY & RESEARCH

My research took place before, during and just after the financial crisis of the late 2000s. Given the peculiarities of block grant funding from the UK government to the Scottish Government, and then from the Scottish Government to Health Boards, the Scottish NHS only began to feel a significant financial pinch in 2011/12. Accordingly, my fieldwork was conducted during the end days of a golden period of NHS funding, and even with promises from all sides to protect NHS funding it seems inevitable that rationing and difficult decisions will become more common. Public involvement will be both more complex, and more crucial in an era of contentious decisions about closing buildings or reducing service availability. Funding for activities which contribute to the assemblage of involvement – particularly the outreach work which in Rivermouth was done jointly with the local authority youth work team – may be restricted. With this in mind, this concluding chapter moves from reflections on involvement and participation in the broadest sense to more specific reflections on what my research offers to future policy-makers, and to policy analysts. Firstly I discuss the implications for health policy in Scotland, touching on both the generalities of public involvement and two more specific examples of current policies. I then move on to draw out some implications for future empirical research.

REFLECTIONS ON POLICY

In chapter 4 I highlighted the way in which Donna's project report transformed her focus group participants' words into clear-cut recommendations to the CHP. Given my concerns about this process, I am aware of the irony of replicating the process by making recommendations here. In a research report on the recovery movement in mental health, Smith-Merry, Sturdy, and Freeman (2010, p. 34) liken their role in suggesting 'further thoughts' to a peer support worker: "What follows here are no more than prompts – invitations perhaps – to further discussion". I like this sentiment, and I will take the opportunity to avoid a neatly bullet-pointed to-do list for policy-makers or practitioners. However, as Collins and Yearley put it:

“Those of us engaged from day to day with the problem of reflexivity would, if they could achieve their aims, know nothing at all... In spite of this achievement, all of us, however sophisticated, can switch to modes of knowing that allow us to catch buses and hold mortgages” (H. M. Collins & Yearley, 1992, p. 302).

Given that this project began taking seed while sitting at a desk facing practical tasks about how public involvement is ‘done’, it seems disingenuous not to ‘stick my neck out’ sitting at a different desk five years later. I am not required to make the big leaps that Donna had to (I do not have to turn Megan’s pitiable “I could have greet” into a recommendation to empower patients through this or that mechanism). Nevertheless I believe that small-scale qualitative projects such as this do offer ‘useful’ insights, and that researchers have a responsibility to package these for people without the time or inclination to read hundreds of pages.

I will not restrict myself (as Eliasoph (2011) does at the end of her remarkable ethnographic account of youth empowerment projects), to neat, practical suggestions to make PPFs better now, but nor will I simply point to complexity and contingency and then stop. I hope that this project can instead unsettle the assumptive worlds in which policy is framed. I restrict myself particularly to thoughts on the current and future direction of health policy in Scotland. This is partly because I feel too few scholars see Scotland, and likely the devolved nations of the UK more generally, as systems in need of investigation in and of themselves, rather than as a tool in a rather tired debate about national character and its manifestation in policy. I would like to contribute to an outward-looking, open approach to policy analysis in Scotland without simply worrying away at the question of what England should learn from Scotland, or vice versa. However, this focus on Scotland is also a more intellectually-informed statement about the need for tailored, context-specific approaches to participation, not toolkits and typologies intended to apply across any organisational structure. The current structure of the NHS in Scotland – a hybrid between the traditional command-and-control hierarchy and the modern, fluid network – poses particular opportunities and challenges, which I will try to address here.

In chapter 2 I argued that there is as close to a consensus as one is likely to get in the academic literature that health professionals and managers stop public involvement from 'succeeding'. Martin's research has done a great deal to shift academic analyses from easy finger-pointing at on-the-ground actors who fail or subvert engagement, to point instead to the tensions contained in English public involvement policy as framed at the centre.

"The openness of the brief for user involvement ... – which demanded that staff recognize the legitimacy of participation, but did not specify the terms of that legitimacy – reflects the frequent vagueness with which these broad policy intentions are translated into practice. Consequently, implementation becomes a matter of negotiation, in which divergent rationales (whether adopted for instrumental or substantive reasons), reflecting different constructions of the relationship between the public, the state and professional expertise, coexist in tension, and are resolved pragmatically rather than on the basis of normative agreement or policy goals." (Martin, 2008b, p. 1765)

However, it seems somewhat naïve to simply point at the 'openness' of policy language, and then (metaphorically) run away. Interpretive and deliberative accounts of policy recognise that ambiguity is an inherent property of policy, and part of what allows it to be agreed on, written in documents and PowerPoint presentations, and enacted at the local level: "[Interpretivists] accept the multivocality of political life as human reality. Recommendations to eliminate ambiguities of policy language are seen as deriving from a mechanical metaphor of social reality that is an inappropriate understanding of human reality" (Yanow, 1987, p. 110).

We cannot, therefore, expect 'better' policy to resolve all our concerns. There is, however, scope for clarification on specific points: "clarification of the purposes of participation is therefore crucial, and initiatives which are not clear about this, or which have one or more purposes, may create confusion and undermine the ability to produce successful outcomes" (Bochel, et al., 2008, p. 202). Where policy entreats staff to involve 'the public', it should be clearer whether this means simply creating an opportunity for all-affected to take part (knowing full well that the vast majority will not), or actually going out and ensuring that the views of the affected (however defined) are heard. More accurately, it should acknowledge that this voice is not simply heard but is generated,

since the public is unlikely to be sitting at home expressing their thoughts on health service management: “Sometimes, rarely, there is a community voice, clamouring to be heard, but it is usually too angry, resentful, deeply felt, tightly exclusive, or politicised for these programs” (Eliasoph, 2011, p. 252). Creating designed mini-publics with careful sampling on demographic grounds, as some suggest would solve the problem of unrepresentative participants (Warren, 2009a), would entail a rejection of this voice where it does exist, and render the exercise all mobilisation and minimal participation. Likewise, the word ‘involvement’ has allowed two decades of policy to be produced which holds little shared meaning. Policy should specify whether it wants the public (or its representatives) to make decisions, to be given the opportunity to express their views on decisions being made by other people, or to do work like conducting consultations or manning hand hygiene stalls. These are vastly different tasks, and there is scope for policy-makers to offer a great deal more specification than they hitherto have.

The current SNP Government in Scotland has placed public involvement at the centre of its vision for a ‘mutual NHS’ (The Scottish Government, 2007). While the current rhetorical popularity of mutuality in the public services appears to be out of all proportion from practical measures being taken to accomplish it, it is certainly a fashionable approach, at the very least in Government publications (Cabinet Office, 2011; Department of Health, 2011; The Scottish Government, 2007). However, as Birchall cautions, there is more to mutuality than a simply enhanced role for the public (Birchall, 2008, p. 5). As regards its potential within health services, I feel that its application to universal, as opposed to bounded, exclusive organisations, may be its downfall. Mutuality in the public sector and in health care has a long pedigree (Birchall, 2001; Gorsky, Mohan, & Willis, 2005) but is more often associated with non-universal, indeed explicitly exclusive organisations, where members have clear relationships with, or stakes within, the organisation. While I recognise and defend the importance of the NHS to the whole population of Scotland, on a day-to-day level this commitment is relatively abstract, more likely expressed by ticking a box listing NHS funding as a priority on a survey than in playing a more active role. In experimenting with membership models for the elections for Boards of Governors, English Foundation Trusts found that opt-out (i.e. universal) membership was an expensive exercise which yielded dramatically low election turnout (Day & Klein, 2005). By contrast, the SNP’s

mutuality rhetoric is overtly inclusive, indeed often linked with the equalities agenda, and seeks to bring all the 'people of Scotland' into a closer relationship with the NHS. On the basis of this research, I would suspect that mechanisms designed to demonstrate or build a 'mutual' NHS will quickly prove to be as 'unrepresentative' as other public involvement mechanisms. The more work you offer to members of the public, the more you restrict likely take-up to those who care a great deal about the NHS, and it seems unreasonable to accept their voluntary activity and then criticise them for their demographic characteristics, or indeed for the very consistency of their presence.

The amount of power or control available to members of the public who participate in public involvement has been pushed up the agenda by current debates about the membership of Health Boards. The SNP administration has made a flagship policy of its determination to make non-executive members of Health Boards directly elected by the public: "Elected health boards will give power back to local people. They represent a major boost for democracy and accountability. They are the best way of ensuring that boards will no longer be able to ride roughshod over community opinion, as has happened in the past" (Nicola Sturgeon quoted in *The Scottish Government*, 2009, p. 1). After encountering significant parliamentary opposition, the policy was reduced to pilots of election and alternative models of appointment, with an independent evaluation (in which I am involved) reporting to Parliament in 2012. While the results of that study are as yet unknown, it is worth reflecting on what my PhD research suggests about the philosophical issue of the initial proposal for elections. Although allowing the public to elect the majority of members of Health Boards (the number of Executive members has also been reduced) may seem straightforwardly to fall within Arnstein's (1969) top category of "citizen control", I hope that my conceptual critique of this literature and my account of the practices of involvement and participation suggest a more nuanced conclusion. Indeed, Rudolf Klein argues that involvement and election belong to entirely different logics of organisational accountability:

"The first is to argue that legitimacy derives from *who* takes the decisions. The second is to argue that what matters is *how* those decisions are taken. The first line of argument leads to the conclusion that the NHS suffers from a 'democratic deficit' and that election is indeed better than selection... The second line of argument puts the emphasis on the decision making process: the remedy is for the process to be transparent, to provide

opportunity for challenge and to involve those affected by the decision” (Klein, 2010, p. 289).

This exclusive focus on ‘who’ makes the decision seems unlikely to enhance meaningful engagement (to improve Barnes’ (2004b) dialogue between private lives and public policy) unless it also has consequences for ‘how’ decisions are made. In short, elections alone are likely to further only a very narrow type of citizen control, and one which is arguably already present given the existence of non-executive Directors.

One advantage of simply casting a vote is that it is a low-cost form of participation, which avoids some of the bravery and energy required for the participatory opportunities currently available through public involvement. For an unhappy citizen, it allows a brief, anonymous opportunity to exercise some control. At first glance it shares this characteristic with a minimal understanding of Hirschman’s ‘exit’. While for Hirschman the fact that voting seeks to change the organisation places it inexorably in the category of voice (which he describes as messy and public in comparison to the “neat and impersonal” tactics of exit), placing a tick in a box seems if anything neater and less personal than terminating a relationship with one health professional and taking up with another. Here, as elsewhere, we see the veracity of Barry’s (1974) assertion that Hirschman’s influential juxtaposition of economic and political logic lacks any concept of the social. However, while voting might be a low-cost mode of participation, it remains an ‘insider’ tactic, in that it concerns itself with cooperating with many other citizens to try to influence the system as a whole. This contrasts with my young adult interviewees’ preferences for ‘outsider’ tactics which allowed them to get what they need without taking part in any collective activity.

REFLECTIONS ON RESEARCH

While chapter 7 offers a theoretical analysis of participation, I would like here to reflect specifically on how my project might inform future empirical research. Conducting this research has revealed some of my own assumptions about participation, in addition to broader findings about Rivermouth, Scottish health policy, and young adults and health. These assumptions were shaped by practical experience, but also by an extant literature

which has found a critical stance largely by emphasising the perceived obstruction of an idealised public voice. Angen argues that substantive validation of interpretive research “includes a consideration of one’s own understandings of the topic, understandings derived from other sources, and an accounting of this process in the written record of the study” (Angen, 2000, p. 390). As other scholars have noted, participation is simultaneously evasively difficult to pin down, and instinctively understood as a ‘good’ thing by most people (Harrison & Mort, 1998). This creates specific challenges for empirical research, not just in defining the parameters of research, but in conducting a research project which has at its centre a sacred cow.

As this thesis demonstrates, researchers have often resorted to allocating blame to specific practitioners or to the policy which drives participation, leaving the central goal of participation untouched. Instead, I advocate worrying away at the phenomenon of interest (or “being perspicacious” about a concept (W. Brown, 2006, p. 205)), simultaneously “recognising popular doubts and desires, aspirations and anxieties and making them public” (Newman & Clarke, 2009, p. 185) and, in a tradition we have learnt from ethnographers, making ‘participation’ strange (Li, 2007b). Crucially, this means recognising the difficulty of expressing qualms and reservations about discourses which are not merely powerfully driven by policy-makers, but also by other actors with whom we might have more ideological or instinctive sympathy. In order to do this project properly I had to step out of a policy frame, but also to wean myself off the newsletters and blogs of non-governmental and academic advocates of participation, in order to recognise an often uncritical and occasionally evangelical frame there, also. As one article asserts “A more positive view of citizens and what they can achieve leads to a stronger commitment to participation. Such “strong democracy’ enables people to see beyond their immediate self-interest and engage in collective decision-making that is transformative and positive” (Lowndes, et al., 2006, p. 282). Even now I struggle to distinguish the normative from the descriptive in this statement, and with such a starting point it seems unsurprising that the article offers suggestions to ‘remedy the failings’ of current practice. We cannot make participation strange, in order to understand it better, if it is such a basic good that its content is never questioned.

The development of a more critical approach was facilitated by understanding the standpoint of my young adult interviewees, and exploring the possibilities to see participation from there. What seems remarkable in hindsight was that I found my interviewees' lack of interest so alien, when it closely resembles the attitude of most of my friends and families outside of professional networks. In this case the existing literature on participation and on public involvement specifically had supplanted more familiar frames from my own everyday life. This is instructive in terms of the conduct of empirical research. Beginning the research process with a review of the existing literature on a topic became, in this case, a long and unsatisfactory task in which I became frustrated with the literature but struggled to articulate the reasons why. Comparing my progress with the clean, linear accounts of research from journal articles and books, I was reluctant to progress to fieldwork without a defined theoretical framework from existing research. Had I not been advised by my supervisors to simply start piloting, I am unsure how long I would have kept reading, ever wider, in search of a comfortable starting point. Piloting was a startling, valuable experience. The early injection of a pragmatic, understated, and uninterested public voice, rarely found in existing literature, transformed the direction of my research. Much interpretive policy research places at its centre the views of local "epistemic communities" (Yanow, 1996). However my project demonstrates the benefits of supplementing this naturalistic, ethnographic approach to recruitment with purposive sampling (Yanow, 2006a). Crucially, this project demonstrates the value of continuing to seek the views of less-heard members of the population, even when they themselves (and other participants in the research) deny that they have any worthwhile input to make.

Including a group with less to say about a specific policy requires the researcher to demonstrate patience and flexibility. In a peculiar inversion of much data collection, attention must be paid to silences, as well as to expressed views. This research project has underlined the importance of listening fully to one's interviewees, and trying to avoid emphasising simply those moments when they say something that one knows will be a 'great quote'. Silences and absences within interviews are not comfortable. At one point in the research I considered resorting to focus groups, on the basis that it may be less intimidating for a reticent interviewee to be part of a group, and not just sitting with an interviewer in silence. This is a common approach in research on young people and political participation (Marsh, et al., 2007; Sloam, 2007). Marsh, O'Toole, and Jones

(2007, p. 71) justify their use of what they term 'ethnographic focus groups' on the basis that it enables them to restrict the facilitator's intervention, making the process more 'respondent-led'. They then follow up with individual interviews to "draw out anyone who had been more reticent, and to explore any differences that had emerged" (Marsh, et al., 2007, p. 73). I suspect that in both interviews and focus groups, exacerbated by the process of transcription and coding, we tend to over-emphasise moments of engagement and connection (particularly those which confirm our hunches or clearly dispute them) at the expense of the times when our questions or prompts appear to make no meaningful connection with our interviewees' lifeworlds. These moments of confusion or silence are, perhaps, mentioned in a methodology section, or put down simply to poor questioning and confined to our internal records of interviews which we would prefer to forget. However I would argue that their inclusion in our research findings is a more genuinely respectful way to place respondents at the centre of research. Marsh, O'Toole, and Jones make an admirable and clear statement of their desire not to impose their definitions on to young people: "It was crucial for us to adopt an approach that avoided, first, predicating the definition of political participation on the researcher's definition of politics ... and, secondly, equating non-participation in a set of activities specified by the researcher with political apathy" (Marsh, et al., 2007, p. 69). However, allowing for the possibility of a genuinely negative response (including silence) entails its inclusion as a finding. In some ways multiple choice surveys may do better at catching this sort of information, although I suspect that low response rates, rather than being a problem to be solved through persistent follow-up, may be the equivalent of a perplexed shrug in an interview.

Designing research which can sensitively elicit people's accounts of their everyday lives, and moving from this to "develop theories that go beyond everyday knowledge to include social conditions of which social actors may be unaware" (Blaikie, 2000, p. 116), seems to me not merely a worthwhile but an essential task of policy analysis. In this, I have often found sociological literature more useful than the traditional policy or political science canons. It seems that sociological literature more often finds people's everyday accounts inherently interesting, and worthy of attention not merely as they cast light on a pre-defined issue. Nevertheless sociology has its own blind spots. In a review of sociological research on organisations, Davies (2003, p. 174) reflects on the dominance of "micro-level, interactionist and phenomenological" approaches in which

“organisations – in the sense of formally established goal-oriented structures with clear authority structures and boundaries – were the backdrop to the analysis rather than the subject of the investigation itself”. She cites the development of public involvement in the NHS as a theme with clear potential for sociologists of health and illness to re-engage with formal organisations, concluding that the ‘modernisation’ agenda in health policy contains a recognition “albeit fleeting, imperfectly sustained, and influenced by power relations from the past – that healthy lives and healthy organisations are deeply intertwined” (Davies, 2003, p. 183). In essence, this approach to research, like public involvement itself, seeks to bring the everyday lives of citizens and the structures and organisations of the state into closer dialogue (M. Barnes, 2004b). I hope that in incorporating sociological attentiveness to everyday life into a more conventional policy analysis project I have made some contribution to this dialogue.

FUTURE DIRECTIONS FOR RESEARCH

As well as these more general thoughts on empirical research, which will inform my future practice, this research project suggests a number of future avenues for research. While studies of social class are currently somewhat unfashionable in social research (Sayer, 2002) there is scope for further work on social class and participation, in order to understand better whether patterns of avoidance and resistance which I identified in my sample of young adults are particular to the somewhat marginalised societal positions which many of them occupied. Given how rooted accounts of ‘everyday creativity’ were in shared social and familial practices of ‘going to the doctors’, it would be valuable to understand whether the tactics my interviewees described vary across class boundaries. For instance, the greater geographical mobility of many university students seems to create interesting relationships with health services; for example, several pilot interviewees described selectively ‘saving’ health problems for visits home.

Largely as a consequence of my skewed samples (with few women in the PPF and few men in my sample of young adults), gender is similarly under-explored within this research. Drawing on Newman’s forthcoming research on women and the labour of activism, there is scope to explore the extent to which the different modes of participation I identified within the PPF are gendered, as well as more broadly whether

these modes have relevance in other participatory forums. Gendered differences in health and health service use are well-researched, but I am particularly interested in whether and how these differences correlate with views on participation and complaints. Young women in my sample who had children repeatedly distinguished between complaining about their own care and that of their children (Rebecca: *When it's your son you would dae anything for him, you would protect him, and he's probably, I wouldnae say more important but you know what I mean eh. It's like wi' him you would do things that I wouldnae dae for mysel'*). I would like to better understand how motherhood alters women's relationships with the state and public services.

Finally, I am intrigued by how the polite, consensual discussions which took place in the formal mechanisms of public involvement and the understated, careful way that interviewees described their own health-care contrasts with the emotive controversy around unpopular decisions to close or downgrade hospital buildings. Throughout this project I expected overt conflict around health services and found very little, and yet hospital closures remain one of the few issues on which campaigners can be elected to Parliament (Rivermouth, as with most local areas, had its own history of closure and opposition). Health policy experts such as the King's Fund consistently call for "reconfiguration" of hospitals to be protected from the interference of elected politicians (Imison, 2011), and yet they have also historically advocated enhanced public involvement (W. Anderson, et al., 2002). I would like to understand better the particular resonance of the 'bricks and mortar' of hospital buildings, and why they manage to transform the generally polite and apparently technical business of health service governance.

CONCLUSION

This project could not have developed in the way it did under most research funding. The luxury of PhD funding enabled me to reshape the project in response to early findings. The scope to embrace the ideas of avoidance and everyday creativity – to seek to understand this realm of under-researched behaviour – with little regard to the immediate consequences for public involvement policy would be difficult in most commissioned projects. Katherine Smith (2010, p. 190) writes of the squeeze on

imaginative spaces within academia, as researchers, driven by funding, are pressured to “explore issues in ways that are applicable to current ‘policy realities’”. Having worked in the policy world before returning to academic study, I understand the frustrations when potentially relevant research fails to ‘help’ in a straightforward way. However there is nonetheless significant value in research which offers new ways to think about important issues (K. Ward, 2005), and it is this type of policy relevance to which I aspire. This project does not simply uncover an uncomplicated truth: it has not necessarily answered the practical questions which were foremost in my mind when I designed it. In emphasising the (organisational and public) labour inherent in participation, and in exploring the alternative tactics by which ‘ordinary’ members of the public exert agency within the NHS, it poses a different set of questions which can, in their own way, also prove ‘helpful’.

Relationships between policy and research are complicated and potentially problematic. In chapter 2 I emphasised the inter-connections between research and policy in literature on public involvement in health. The development of a body of commissioned work during the heyday of New Labour’s ‘evidence-based policy’ institutionalised an approach predicated on the unfulfilled potential of participation, and on the inability of either policy or NHS staff to ‘do’ involvement properly. Awareness of the “unachievable fullness” (Laclau, 2005, pp. 70-71) of public involvement is not a convenient or ‘helpful’ finding for current policy-makers. Accordingly it lurks beneath the surface of multiple studies which seek to ‘remedy the failings’ (Lowndes, et al., 2006) of current participatory practice. By seeking to ‘make involvement strange’ my research moves away from the orientation point of ‘successful’ or ‘real’ participation, and explores instead the range of meanings and practices present in one case study.

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APPENDIX 1: ACRONYMS

CHP	Community Health Partnership: smallest administrative unit of Scottish NHS 2004-present. Tasked with involving local communities and integrating health and social care.
CPPIH	Commission for Patient and Public Involvement in Health: national body for patient and public involvement in English NHS 2003-2008.
MREC	Medical Research Ethics Committee.
MSYP	Member of the Scottish Youth Parliament: young people elected in schools and colleges to represent their area in this national body.
NHS	National Health Service.
NICE	National Institute for Health and Clinical Excellence: agency of NHS, tasked with promoting effective use of resources in NHS in England and Wales 2000-present.
PFPI	Patient Focus and Public Involvement: name for Scottish policy agenda around public involvement and patient-centred services, circa 2001-present.
PPF	Public Partnership Forum: main mechanism of public involvement in Scottish NHS at local level 2004-present.
PPI	Patient and Public Involvement: name for English policy agenda circa 2000-2010.
PPI Forums	Patient and Public Involvement Forums: main mechanism of public involvement in English NHS 2003-2007.
SHC	Scottish Health Council: agency of NHS Scotland tasked with supporting and monitoring Board's Patient Focus and Public Involvement activities.
SNP	Scottish National Party: in power in Scotland from 2007-11 (minority government) and 2011-present (majority).
SPCRN	Scottish Primary Care Research Network: network which provided financial and practical support for this study.

APPENDIX 2: LIST OF INTERVIEWEES

Staff	
Name	Job title
Donna	Health improvement officer
Jennifer	PFPI lead for Rivermouth CHP; administered the PPF
Karen	Health improvement nurse
Linda	Board Equalities Lead
Mark	Team leader, local authority young people's services
Pat	Co-ordinator of local authority youth engagement programme
Shelley	Co-ordinator, local Scottish Youth Parliament office
William	Scottish Health Council local officer

Public Partnership Forum members¹⁰
Charles
Craig
Donald
James
Margaret
Mary
Michael
Richard
Robert

¹⁰ To preserve the anonymity of the PPF members as far as possible, I have not included specific biographical details for individuals.

Thomas

Young adults		
Name	Age	Occupation
Amy	22	Mother & part-time personal service worker
Andrew	19	Unemployed
Chloe	22	Sales and customer service worker
David	21	Professional
Emma	22	Government training scheme
Laura	19	University student
Lauren	20	Sales and customer service worker
Lisa	25	Government training scheme
Megan	19	Sales and customer service worker
Nicole	22	Sales and customer service worker
Rachel	20	Personal service worker
Rebecca	24	Mother & unemployed (job-seeking)
Ryan	24	Government training scheme
Sarah	20	Unemployed

APPENDIX 3: STAFF INTERVIEW SCHEDULE

Explain research.

- PhD research looking at how young adults currently have a voice within the NHS in Scotland.
- Rivermouth as Scottish case study site, due to proximity to Edinburgh and characteristics of population, number of hospitals etc.
- Focus will be interviews with young adults but as well as their views want to have context of what is happening more generally.
- Have made as much use of website as possible – please do just refer me to colleagues or documents as appropriate.

Consent form and explain recording options.

1. Your role
 - a. Responsibilities
 - b. Time in post
2. Overview: main channels of public involvement in Rivermouth?
 - a. Overseeing, or involved in?
3. Have you seen much change? Is Better Health, Better Care changing activities?
4. How much /often does public involvement alter outcomes or decision-making in Rivermouth?
 - a. Any prominent examples?
5. Population as a whole is reasonably engaged, or some groups better represented than others?
 - a. How much of a problem is this?
 - b. How is this dealt with?
6. Young adults, the under 25s, heard in Rivermouth?
 - a. How are they reached
 - b. On all issues or mostly on specific issues?
7. Does the lack of young adults (on the PPF/generally) make a difference?

APPENDIX 4: PPF INTERVIEW SCHEDULE

Explain research.

- PhD research looking at how young adults currently have a voice within the NHS in Scotland.
- Rivermouth as Scottish case study site, due to proximity to Edinburgh and characteristics of population, number of hospitals etc.
- Focus will be interviews with young adults but as well as their views want to have context of what is happening more generally.

Consent form and explain recording options.

1. How did you originally get involved with the PPF Reference Group?
 - a. How much of your time does it take up? Do you think of it as a part-time job? Or a voluntary job?
 - b. Did you join with particular issues/concerns in mind?
 - c. Do you campaign on/work on these issues other than through the Reference Group?
2. How do you enjoy your role as a member of the Reference Group?
 - a. Do you plan to stay involved?
3. How much do you draw on your own experiences with the health service in your work as a member of the Forum?
 - a. What other knowledge do you draw on?
4. What do you see as the role of the PPF Reference Group more generally?
 - a. Campaigning/issue-led role?
 - b. Consultative role (responsive)?
 - c. Relation to wider PPF database
 - d. Do you think the reference group works?
5. How well do you feel members of the reference group represent the public in Rivermouth?
 - a. If not, why do you think this is?
 - b. Do you see this as a problem?
6. Thinking particularly of issues that might concern young adults in the area, do you feel their concerns have been voiced through the group, or through other channels, or not?
 - a. Do you come into contact with/speak to any young adults?
7. Why do you think there aren't members of the reference group in the 25 and under age group?

- a. Do you think the reference group would benefit from having younger members?
 - b. If not, why not?
- 8. Do you think of yourself as interested in politics, or not?
 - a. Do you see your role in the Partnership Forum as a political one, or not?

APPENDIX 5: YOUNG ADULTS INTERVIEW SCHEDULE

Introduction

- Introduce self and study:
 - This is a research project looking at how 18-25 year olds in Scotland feel about the NHS and what the NHS is doing to respond to those feelings at a local level.
- Explain content and structure of interview
 - We'll start with some basic questions about you, then talk a bit about your health and how you use the NHS, and how happy you are with that. Then there is a short section on what the NHS does to give the public more say in how it runs, and then we'll finish up with a few questions about living in Rivermouth generally, and politics. If there are any questions you don't want to answer, that's fine, and you don't need to give me a reason for that.
- Explain timing and recording options
- Explain confidentiality
 - No-one in Rivermouth is going to hear the interview or read the transcript. If there are any bits of the interview that I use in any reports or publications I will make sure no-one can identify you from that, so anything you tell me is confidential. The only exception to this is if in the conversation something came up which I felt I needed to report to the police. That is very unlikely, and would only be something involving serious harm to someone else – so any minor actions that came up – including things like drugs, will be kept confidential.
- Time for questions: consent form (and voucher given at this point)

About you: check & expand on details from questionnaire

- Age
- And are you working at the moment?
- Where are you living at the moment, with family or elsewhere?
- (Family status)
- Permanence: time in current location, see yourself staying around here?

General health

- How is your health generally?
 - Do you have any health problems at the moment?

- Some people live quite healthy lifestyles and others find it more difficult. How healthy do you feel your lifestyle is?
 - Have you tried to make any specific changes to your lifestyle to try to be healthier?
 - Do you worry much about your health, or not?

Health service use

- How long have you been with current GP practice?
 - How did you come to register with this practice? (Why?)
 - How do you find it generally?
- Is there a specific doctor in the practice that you like to see?
 - Or any that you prefer not to see?
- How many times would you say you have seen your GP in the last year? Is that usual for you?
- Talk through your most recent visit to your GP (detail, 'silly' questions)
 - Why did you decide to visit the GP?
 - How did you make the appointment? (open access, pre-booked, booked on the day, specific doctor)
 - How did you travel to the surgery?
 - How do you find the reception?
 - How was your wait before you went in to see the doctor?
 - How did you feel about the appointment?
 - Is that usual for you?
- Are you registered with a dentist? How long have you been with that dentist?
- *How many times have you seen your dentist in the last year? Is that usual for you?*
- *Tell me about the last time you visited your dentist*
 - *Why did you decide to visit the dentist?*
 - *How did you make the appointment? (pre-booked, emergency)*
 - *How did you feel about the appointment? Is that usual for you?*
- Has your GP ever referred you on for tests or treatment elsewhere?
- *Tell me about that appointment*
 - *What was it for?*
 - *How was the appointment made? (with GP, sent out from hospital, self-booked)?*
 - *How did you feel about the appointment/treatment?*
- Have you even been to Accident & Emergency? How many times in the last year?
- *Tell me about your last visit to A&E*
 - *Why did you decide to go?*

- *How did you get there?*
- *What happened?*
- *How did you feel about the visit?*

- Have you ever used any other kind of health service like walk-in clinics for travel advice or sexual health (like the Drop-in Service)?
- Would you tell me a bit about
 - How you found out about that service?
 - How you felt about the service?
- Have you heard of the Drop-in Service at all?

- Do you ever accompany anyone else to any health services? (a child, friend, elderly relative etc)
 - How often is that? (How does that come about?)
 - Can you tell me about the last time that happened?

- Have you ever been on the NHS website? *How often?*
- *How did you find out about it?*
- *Last time you used it, what were you looking for?*
 - *Did you find what you were looking for?*
- What about other websites with information about health? Do you use any of them?
 - What do you like about them?
- Where do you get most of your information about health issues?

- Have you ever called NHS 24? How often?
- How did you find out about them?
- Last time you called, what did you call about?
 - Did you find them helpful?

Health service attitudes (drawing on experiences given so far)

- Has anyone ever asked your views on the NHS before? (Like a questionnaire or anything?)
 - *How was that?*
 - *Would you like the opportunity to give your views?*
- How have your visits to the doctors changed as you have gotten older? Do you need or want different things now?
- Thinking about the visits to the doctor, dentist and hospital we've spoken about how happy are you with your experiences of NHS services here?
- If you were unhappy about some part of your visit to doctor, would you do anything about it?

- Who would you talk to about it?
- Would you complain?
- How do stories you hear from friends and family compare with your own experiences of the NHS in Rivermouth?
- What about stories about the NHS in the news? How do they compare?

Voice or choice specifically:

- In the last couple of years a committee of local people have been discussing the NHS here and how it's doing, and how it can get better. It's called Public Partnership Forum? Have you heard of it?
 - *(If yes: what have you heard, where did you hear?)*
 - *(If no: explain about big group that gets emails and letters, and small group that meets)*
 - Does you think that sounds like a good thing for the NHS in Rivermouth?
 - They have found that very few young people are joining. Why do you think that might be?
 - Would you ever consider going along to a meeting of the PPF, or being on their database if they want to send out a questionnaire etc?
 - What would put you off taking part?
 - What would encourage you to take part?
- Something that has been more popular in the English NHS is letting patients choose which hospital they go to if their GP sends them for further tests or treatment. (name possible local hospitals) Popular hospitals get more money than unpopular ones.
 - How does that idea sound to you?
 - If you were going to hospital for something, would you want to choose? How would you choose?

Political participation

- Do you think of yourself as interested in politics?
- How do you find Rivermouth as a place to live?
 - Are there things you would like to change about it?
- Are you involved in any community groups in Rivermouth? (e.g. football team, youth forums)
 - (How did you get involved with that?)
 - (What is your role there?)
- Have you ever voted? (local, Scottish Parliament, UK Parliament, European elections)
 - (Last time you voted, how did you go about deciding who to vote for?)
- Are you aware of the Scottish Youth Parliament, and it's members MSYPs?
- Are you involved with supporting any national organisations? (e.g. Oxfam, Amnesty, cancer charities)

- Are there any national causes you feel strongly about?

Finish up

- All my questions: anything you'd like to ask?
- Thanks for your time.
- SNOWBALLING
- Make sure have my contact details