

**Patient and Public Involvement (PPI): Developing a conceptual framework from
an exploratory study of three healthcare providers**

By

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Abstract

PPI has been growing considerably in the last 15 years in the UK's National Health Service (NHS) following shifts in the relationship between institutions and the public. Various legislative changes during this period have moved the NHS towards a consumerist model of delivery with a greater emphasis on the voice of their service users and the public. High profile cases, such as the severe failings at the Mid-Staffordshire NHS Foundation Trust (Francis, 2013), have provided impetus for PPI. However, despite increases in PPI-related activities, research into PPI methods and their impact have indicated that both methods and impact are difficult to evaluate (e.g. Conklin et al., 2012). Many existing models of PPI appear to over simplify what is a complex social phenomenon. Relatively simple early models such as the ladder of participation (Arnstein, 1969) are still widely referenced. Many studies have focused on individual PPI activities and individual stakeholder perspectives but have paid less attention to the commonalities and differences across and within stakeholder groups and PPI contexts.

This study explored the complexities of PPI by collecting detailed observational, documentary and interview data from three different healthcare provider organisations (a mental health trust, a social enterprise, and an acute hospital trust). A range of methods (observations, semi-structured interviews, and document reviews) were used to explore in depth the complex nature of PPI and capture detailed data about contextual and organisational factors. Furthermore, whilst this study aimed to explore a range of activities and individual perspectives across multiple organisations, the ultimate outcome of this research was to produce a conceptual framework that extends theory by placing greater emphasis on the influence of contextual and societal factors.

This study identified a plethora of factors that contribute to successful PPI; some of which had been found in previous research (such as personal barriers for laypeople). The constraining role of organisational structures and hierarchies; the strong influence of Government policies and initiatives; and the gatekeeping role of PPI facilitators were novel to this research, or added nuances to existing literature. With regards to the latter, a key finding was the significant role PPI facilitators play in both the implementation and success of PPI work. Their role is essentially a mediator between their employer and patients and the public.

This study identified that the role of the voice of patients and the public is negotiated via PPI facilitators, making these key to the success of PPI. PPI facilitators were both responsible for facilitating PPI activities and reporting back the results of that work to senior management (including Board members); the ultimate goal of which was to influence service improvements as well as long term organisational strategies. These findings indicate that a conceptual framework of PPI is needed that considers not just individual perspectives and methods of PPI, but also the process of negotiation via PPI facilitators in making PPI a success.

Preface

This PhD research project, whilst being primarily about contributing to theory on a complex topic, was originally borne out of frustrations practising in the field. During my work at a Strategic Health Authority (SHA) where our focus was on service improvement, a frequent frustration was that the excellent efforts we made to involve service users and their families in service developments had little impact, or at least appeared to. My observations at the SHA were that we were, in effect, a mediator between patients and the public, and organisations that provided services for them. We were also a mediator between the Department of Health (DoH) and organisations that commissioned and provided NHS services. This meant that two things happened: firstly, our service improvement and PPI initiatives were helpful to providers and commissioners but frequently ‘put on the back burner’ by them for various reasons (e.g. their own limited capacity and time constraints); and secondly, goalposts were frequently moved by DoH, meaning that valuable improvement work was rendered pointless in the wake of a new priority.

One of the unique aspects of this PhD project is that the aim of being able to contribute to practice was achieved before the project completed. This is because I was able to obtain employment in one of the case sites before the analysis and write-up was completed. Each organisation was provided with a report detailing observations made in each case site, including a comparative summary of the case sites, and recommendations for improvements, at the end of the data collection period. Presentations were also delivered at each site summarising the key findings. Following receipt of the report and the presentation, I was approached about a new post in Case Site C, the acute hospital trust. Following securing employment, I was able to work with a newly established team to improve and expand PPI activities, working with a range of stakeholders across the organisation and externally. These valuable experiences have helped to add an additional level of interpretation of the data, from a practical application perspective, that would not otherwise have been achieved. From a personal viewpoint, for me, this means the circle is complete. I practised in the field and felt I couldn’t achieve what I wanted to; I spent time to look at the field from the outside; and finally returned to the field and have been able to achieve some of the things I wasn’t able to before, having developed a greater understanding of this complex work.

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Summary of abbreviations

AHFT	Acute Hospital Foundation Trust
APHO	Association for Public Health Observatories
AQP	Any Qualified Provider
BME	Black & Minority Ethnic
BPS	British Psychological Society
CCG	Clinical Commissioning Group
CHC	Community Health Council
CPPIH	Commission for Patient & Public Involvement
CQUIN	Commissioning for Quality & Innovation
CRB	Criminal Records Bureau
DNA	Did Not Attend
DoH	Department of Health
FFT	Friends & Family Test

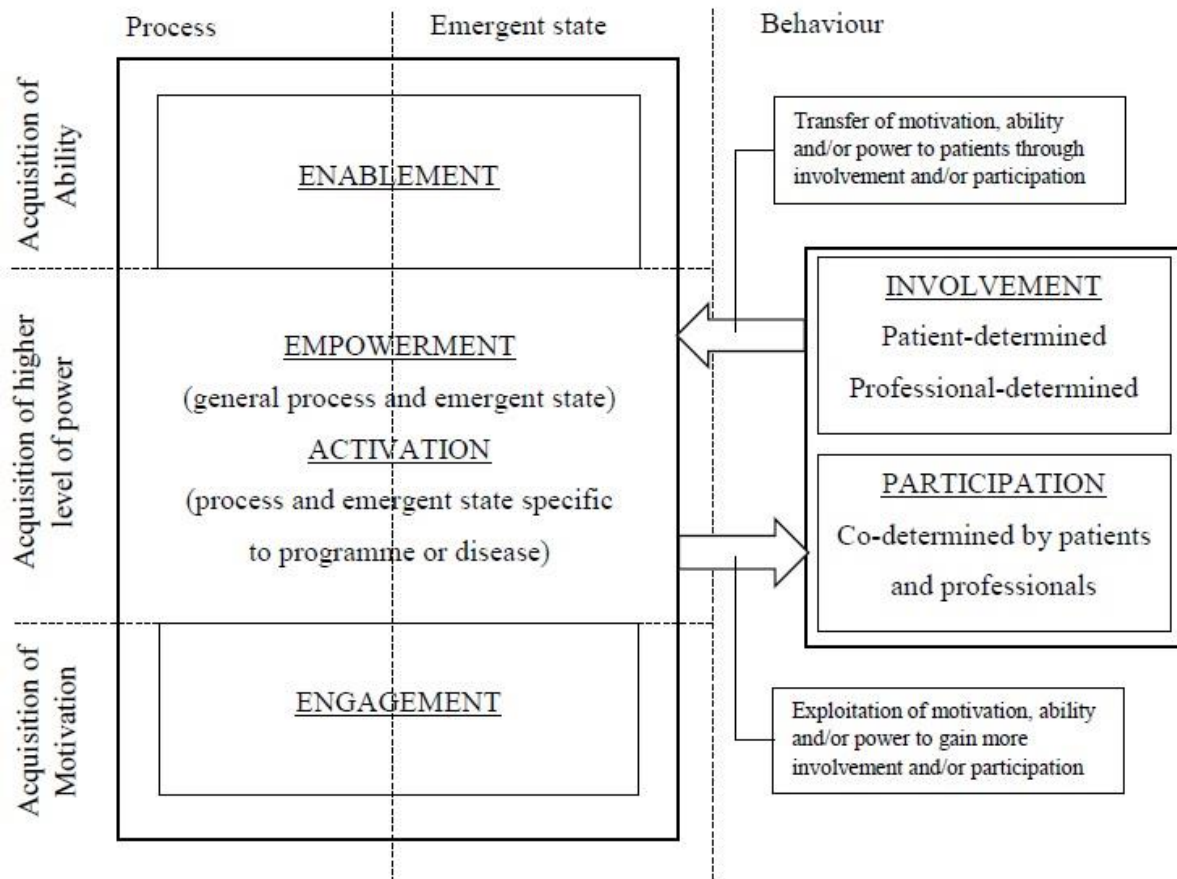
FHP	Family Health Partnership
GP	General Practitioner
HRA	Health Research Authority
HSCIC	Health & Social Care Information Centre
KPI	Key Performance Indicator
LGBT	Lesbian, Gay, Bisexual & Transgender
LINKs	Local Involvement Networks
MHT	Mental Health Trust
NHS	National Health Service
NPM	New Public Management
PALS	Patient Advice & Liaison Service
PBC	Practice-Based Commissioning
PCG	Primary Care Group
PCT	Primary Care Trust
PEEG	Patient Experience & Engagement Group
PEG	Patient Experience Group
PIS	Participation Information Sheet
PPG	Patient Participation Group
PPI	Patient and Public Involvement
PROMs	Patient Reported Outcome Measures
PSEG	Patient Safety & Experience Group
R&D	Research & Development
REC	Research Ethics Committee
SE	Social Enterprise
SHA	Strategic Health Authority
TCS	Transforming Community Services

1. Literature Review

The following sections present a discussion of the literature on PPI – the political history of PPI, representation, individual perspectives, practical aspects such as methods, and conceptualisations of PPI. What these sections set out are the complexities of PPI – its lack of clear definition, the inconsistency of methods, the varied perspectives of individuals involved, the multiple facilitating factors and barriers, and its elusive impact. The final section of the literature review presents an overview of various models and conceptualisations of PPI, before presenting the case for a change in the focus of PPI research to further develop our understanding.

Before discussing the complexities of PPI highlighted in the literature, it is pertinent to present a definition of what PPI is. However, this is a difficult task and there appears to be little agreement in the literature (Barello et al., 2012; Carman et al., 2013; Castro et al., 2016; Conklin et al., 2012; Crawford et al., 2002; Forbat et al., 2009; Mockford et al., 2012; Staniszewska, 2009; Tambuyzer et al., 2011). There are multiple interchanging terms used in the literature – ‘involvement’, ‘participation’, ‘engagement’, ‘empowerment’, and so on. Fumagalli et al. (2015) made attempts to remove the ambiguities between these terms in a concept-mapping review of research studies between 1990 and 2013. Interestingly, they found few studies that gave an explicit definition of the term chosen: only 17% of ‘patient involvement’ studies, 29% of ‘patient engagement’ studies, 30% of ‘patient enablement’ studies, and 42% of ‘patient empowerment’ studies gave an explicit definition. Fumagalli et al., (2015) argue this is likely because researchers assume that, because research in this field has a long history, the definitions are already well-known by others. Their concept-mapping research highlighted the overlapping definitions of these terms, as shown in Figure 1.

Figure 1. Representation of tentative concept mapping (Fumagalli et al. 2015: p.390)



Given the lack of consistent definitions in the literature, to ensure there was a comprehensive review of PPI research and debate whilst also being manageable, only some of the above terms were included in searches for articles – ‘involvement’, ‘participation’, and ‘engagement’. These terms were adopted as they seemed to be the most commonly used terms in healthcare (based on reviewing relevant Government policies). As PPI is a widely researched social phenomenon, searches were restricted to between 1st January 2000 and 31st December 2017, with the exception of any articles regarding models and theories of PPI, such as Sherry Arnstein’s (1969) ladder of participation. To illustrate the quantity of research in this field, a search of only the phrase ‘patient and public involvement’ in the title between the years 2000 and 2017 yields 195 results on Google Scholar and 146 on PubMed. When searches are extended to include the terms engagement, participation, and empowerment, results exceed 3,000 articles.

In practice, the search strategy initially involved searches for research articles with ‘patient and public involvement’, ‘engagement’ or ‘participation’ in the titles (articles in

English language). Searches were conducted on Google Scholar and PubMed. Articles regarding involvement in a person's own care and treatment, patient safety, commissioning, or public health, were not reviewed, except for articles with relevant conceptualisations of PPI. This was because, based on early reading of some articles in these areas, it was decided that these areas of the literature were more specific in nature and would have detracted from the main discussions of the literature. Reference lists were also reviewed on each collected article to further aid searches for relevant articles.

Essentially, the main aim of the literature review was to identify and describe the key issues and themes. As such, this is a narrative of the literature on PPI, rather than a systematic review. After initial searches and reading, a first draft of the literature review was made once the key issues and themes had been identified (in other words, once a 'saturation' point had been reached). Further iterations of the literature review developed as further literature was identified (between the years 2013 and 2017 when the final draft was completed). As such, this literature review attempts to convey the key arguments from the literature but it is not possible to discuss all relevant literature due to the scale. Furthermore, it should also be noted that the majority of papers reviewed come from health journals, as this is where most PPI work is published. There were, however, several papers reviewed from healthcare management and public services journals, as well as research methods journals (specifically papers on PPI in research). The types of journals searched were not restricted solely to health, though the majority of papers identified were in health journals.

1.1. A political history of participation: Activism, citizenship, accountability, and consumerism

The following sections describe and discuss the political landscape within which PPI is framed. Since the inception of the NHS in 1948, society has gone through numerous political and ideological shifts. These shifts have changed the relationship between the state and the public, moving from authoritarian public services to consumerism and increased ‘customer’ choice. With each Government change, PPI has changed too, driven by legislative changes. Patients have more involvement in their own care, more choices about their treatment options, and a greater say in how services are run. In more recent years, there has been increasing competition between healthcare providers, greater consumer demands for services, and increasing efforts to make healthcare services more accountable.

1.1.1. Background – how PPI became popular

Patient and public involvement (PPI) has a long and political history, driven by greater public demands born out of a post-war welfare state. The introduction of free healthcare for all through the NHS in England in 1948 was one way in which the public were to be given a better quality of life regardless of their social status. The key principle of the NHS was that it would offer universal healthcare to all and be free at the point of access, having been paid for through taxation. This was the vision of Aneurin Nye Bevan, the health secretary at the time (Campbell, 2016). Although initial intentions were honourable and good, healthcare, like many other public services at the time, was authoritarian and paternalistic. This was particularly the case in mental health, where patients were held against their will in mental health institutions (or ‘asylums’ as they were known) (Felton & Stickley, 2004).

The current picture is, of course, quite different, led by increased demands from the public in the form of protests and lobbying Government (Baggott, 2005). From the late 1960s onwards, societal change was rapid and featured many significant changes to legislation. Laws were introduced to protect people from violence, oppression, and discrimination (e.g. Equal Pay Act, 1970; Sex Discrimination Act, 1975; Disability Discrimination Act, 1995). Mental health institutions were closed and replaced with community-based services to move away from their authoritarian and prison-like approaches (Borg et al., 2009; Felton & Stickley, 2004). Voluntary organisations, and organisations that represented consumers and patients, became more popular during this period as well, such as the Patients Association,

and the Consumers' Association. These organisations were formed because of patients' dissatisfaction with services and a rejection of the paternalistic nature of healthcare (Baggott, 2005; Mold, 2010).

As such, the general arguments for involving patients and the public in healthcare are to democratise it as a public service, increase accountability to the public, and make organisations more responsive to the public's needs. Sang (2004, p.188) provides a useful summary in lay terms about the paradigm shift in healthcare leading to increasing PPI:

- “First, we are all fellow citizens with rights and responsibilities in relation to our own health and well-being. We are all worthy of respect – not convenient labels: ‘handicapped’, ‘depressive’, ‘sufferer’, ‘victim’ and so on.
- Secondly, we need to learn to facilitate dialogue ‘at every level in every process’ thereby shedding the labels and stereotypes we share about one another.
- Thirdly, we need to learn to manage our own lives and health journeys...to enable us to challenge the still dominant dependency culture: ‘doctor knows best’...Working in partnership is a process of mutual discovery and informed consent and the exercise of choice.
- Fourthly, we need to be aware that cooperation within user and carer groups, and across traditional service boundaries, makes a positive difference. Flexible co-operation of this kind is a real challenge to the ‘blame and shame’ culture that often pervades healthcare.”

1.1.2. The introduction of a quasi-market, competition, and the ‘consumer’

In 1979, the Conservative Government began a programme of quasi-marketisation for a range of public services, including healthcare; aimed at reducing inefficiency and driving quality up, as well as giving consumers more choice (Bolton, 2002; Farrell, 2010; Fotaki, 2010; Gibson et al., 2012; Needham, 2006). Of course, the ability of marketisation to improve quality and choice has been questioned (Hanoch & Rice, 2010); nevertheless, healthcare was overhauled and new structures were put in place. The changes during the early 1980s have been characterised as ‘Public Management’, and involved more consumerist ideals of service delivery (Bolton, 2002; Farrell, 2010; Milewa, 2004). One way of framing

the intended outcomes of these reforms is ‘choice’ (consumers choose from a range of services), ‘voice’ (consumers have a say in their own care and the running of services), and ‘exit’ (consumers can reject a service if it is deemed insufficient) (Farrell, 2010; Fotaki, 2010).

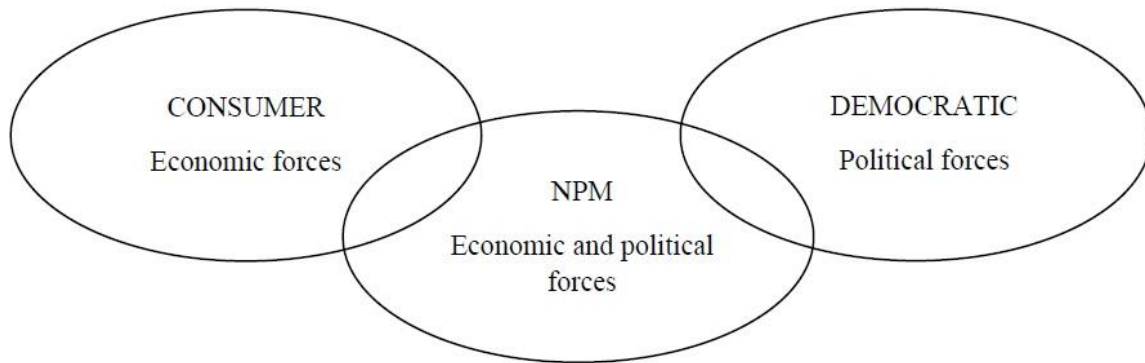
In addition, the NHS Management Inquiry (Griffiths, 1983) recommended tiers of managers at all levels of NHS organisations, with the purpose of managing services led by consumer wishes rather than by the preferences of the dominant medical profession. GP Fundholding (NHS and Community Care Act 1990) was also introduced as a way of purchasing services based on localised needs. These structures can be termed “consumerism by proxy” or “management-led consumerism” (Mold, 2010: p.2 & p.8 respectively). Here marked the first moves away from paternalism to managerialism in the NHS (Limentani, 2002).

These concepts were extended further with the New Labour Government in 1997 – this period has been characterised as ‘New Public Management’ (NPM) (Barnes et al., 2007; Bolton, 2002; Martin, 2009; Rowe & Shepherd, 2002). In 1997, the Best Value Framework introduced a range of citizen forums and agencies, and introduced the 4 Cs: ‘Consultation’, ‘Competition’, ‘Compare’ and ‘Challenge’ (Baggott & Jones, 2014; Barnes et al., 2007; Farrell, 2010). This period has also been referred to as the ‘third way’ in politics (Forster & Gabe, 2008; Pickard & Smith, 2001; Sturgeon, 2014) – managerialist and consumerist concepts “with a human face” (Sturgeon, 2014: p.409). Attitudes towards the delivery and principles of healthcare had changed considerably from the universal and collective principles of the early NHS to the consumerist individualism of today (Fotaki, 2010). Various legislative changes and reforms happened during this period to increase the consumer voice (these measures will be described in section 1.1.4.).

When the coalition of Conservatives and Liberal Democrats came to power in 2010, there were proposals for more far-reaching reforms featuring two major changes: commissioning of healthcare services was to be moved back to the hands of GPs to meet more localised needs (the ‘consumerism by proxy’ model referred to earlier); and significant increases in competition were to be introduced through the ‘Any Qualified Provider’ (AQP) legislation (DoH, 2011b). These changes were met with considerable opposition (see Sturgeon, 2014, for a review of this period), and Tritter & Koivusalo (2013) claimed these

changes merely represented a return to power for the medical elite. A useful summary of the political and societal landscape against which PPI is framed has been provided by Rowe & Shepherd (2002). Figure 2 illustrates the converging and competing fundamental ideologies from which PPI originates, pertaining to both political and economic drivers.

Figure 2: Drivers underlying various models of public participation (Rowe & Shepherd, 2002: p.278)



1.1.3. The influence of scandals

In the early 2000s, there were several high-profile investigations and inquiries into poor care and standards in the NHS. Three of the biggest cases were the Bristol Royal Infirmary Inquiry into the poor cardiac care of children (Secretary of State for Health, 2001), the Alder Hey Children's Hospital infant organ retention inquiry (Redfern et al., 2001), and the Shipman Inquiry into the murders of at least 15 pensioners by their GP Harold Shipman (Dame Smith, 2002). A common clear message from these inquiries was that medical professionals were not robustly regulated and the paternalistic delivery of healthcare meant that few questioned their authority. This led to calls for greater accountability to the public.

In 2013, there was arguably the biggest NHS scandal – the Mid-Staffordshire NHS Foundation Trust failings. Between 2007 and 2009, serious concerns had been raised via various public bodies about the standards of care but without considerable action being taken. In February 2013, Sir Robert Francis QC published his inquiry report into the failings of the trust. Although a finite figure could not be concluded, it was estimated that as many as 400 patients died due to poor care, neglect and even abuse. One of the major findings was that concerns from patients, carers, and staff working for the Trust, were not listened to, leading

to fresh calls for greater public accountability. As such, the NHS was entering a new wave of pressures to improve quality standards, and increase transparency and accountability.

1.1.4. Relevant legislative changes

In response to calls for greater accountability and democratisation of the NHS, various changes have occurred. But in practice, there have been limitations. With legislation intended to bring about choice and voice, it has been found that choice is often very limited (Bradshaw, 2008; Exworthy & Peckham, 2006), such as in the case of emergency situations (of which one third of all patient contacts are). Ensuring the public's voice was heard was also far from simple. State-sponsored structures for PPI have gone through numerous changes, as follows:

- 1970s – Community Health Councils (CHCs) – Local-Authority run panels with lay members to call healthcare providers to account. However, their role and powers were limited in practice (Baggott, 2005). Local Authorities also commissioned healthcare services.
- 1980s – following NHS Management Inquiry (Griffiths, 1983), Family Health Partnerships (FHPs) were introduced – linked to new Health Authorities whom commissioned services, including lay members to scrutinise healthcare providers. CHCs were deemed inefficient by the NHS Management Inquiry but continued to operate.
- Early 1990s – GP Fundholding was introduced in 1990 (NHS and Community Care Act 1990) as part of more reform to allow GPs to commission local services on behalf of their patients, though not all GPs opted into this scheme. This represented introduction of an internal market of competition and incentivisation (Kay, 2002).
- Late 1990s – New Labour Government released the paper *A First Class Service: Quality in the New NHS* (Secretary of State for Health, 1998), the focus of which was on 'partnership'. Primary Care Groups (PCGs) were to replace GP Fundholding and included lay members. This was the first-time laypeople were directly involved in commissioning. Health Authorities became Strategic Health Authorities (SHAs) responsible for monitoring healthcare providers and disseminating DoH guidance. GP practices were also encouraged to set up Patient Participation Groups (PPGs)

(Secretary of State for Health, 1997). There was also increasing prevalence of consumer and patient organisations during this time (Baggott & Jones, 2014).

- Early 2000s – NHS Reform and Health Professions Act 2002 and the Health & Social Care Act 2012 brought about a wave of reforms:
 - CHCs were abolished and replaced by Patient Forums.
 - NHS organisations were instructed to have their own Patient Advice & Liaison Services (PALS) and have accessible formal complaints mechanisms¹.
 - NHS organisations now had a legal duty to consult patients and the public on major service changes.
 - The Commission for Patient & Public Involvement in Healthcare (CPPIH) was set up to oversee PPI across the country.
 - Foundation Trusts were introduced which had to have public membership and an elected Board of Governors to call the trusts to account.
- Late 2000s – PCGs became Primary Care Trusts (PCTs) with much broader remit geographically, moving commissioning further away from being localised. Practice Based Commissioning (PBC) was introduced as part of *Our Health, Our Care, Our Say* (Secretary of State for Health, 2006) to continue with small-scale local commissioning of certain services. Local Involvement Networks (LINKs) replaced Patient Forums and had remit extended to social care (Local Government and Public Involvement in Health Act 2007). The NHS Constitution, which set out patients' rights and expectations, was published in 2009 (DoH, 2009).
- 2010s – Health & Social Care Act 2012 brought about another large wave of reforms (listed below). The GP Contract 2015 (NHS England, 2015) instigated a contractual requirement for all GP practices to have a PPG, where before it was only voluntary.
 - PCTs and SHAs were abolished. PCTs were replaced with Clinical Commissioning Groups (CCGs) – consortia of GPs, other clinicians, and laypeople to commission the majority of NHS provision. This moved commissioning back to being more localised again, but with a bigger remit than GP Fundholding.
 - Competition brought in through AQP which allowed patients to choose from a range of providers for certain services including third and private sector providers.

¹ The success of such measures has been questioned (Cowan & Anthony, 2008; Evans et al., 2008; George & Joseph, 2009).

- LINKs were replaced by HealthWatch groups. This service could be provided by any organisation and, therefore, no longer had to be hosted by Local Authorities.

The frequent changes of legislation, particularly in the last 15 years, demonstrates an ongoing lack of agreement over how to run healthcare services, including how to incorporate patient choice and voice. Milewa (2004) said of the changes in structures at that time that “the mere existence of notionally enhanced access to decision-making domains tells us little about their potential impact upon patterns of power and influence at a local level” (p.245). Baggott & Jones (2014) also noted that, whilst the setup of new mechanisms opened up opportunities for engagement, the “lack of coherence of the new structures undermined these opportunities” (p.2167), and the frequent changes to NHS structures can have a negative impact on PPI opportunities (Petsoulas et al., 2015). Similarly, MacDonald & Taylor-Gooby (2010) stated that “the NHS seems sincere about its desire to involve patients and the public...The conflict seems to be between the need for control, particularly of finance, and the need at the same time to devolve power downwards to the local level” (p.14). As such, it appears there are ongoing tensions between top-down and bottom-up approaches to healthcare management, as demonstrated by the numerous legislative changes listed above.

1.1.5. Summary

Throughout these past 30-40 years, what is apparent is that there has been a tension between bottom-up locally run services, and top-down challenge and accountability (MacDonald & Taylor-Gooby, 2010). NHS organisations become more locally-driven through various initiatives but the Government is challenged by the public to step in and, in response, implements further top-down accountability (Gustaffson & Driver, 2005). The latest Government has returned us to locally driven services with a greater emphasis on the local voice, albeit partly via their GPs in commissioning services, whilst also introducing further marketisation through the AQP legislation (DoH, 2011b). Tritter (2009) helpfully summarises that PPI has been driven in response to three tensions in society: individual/collective; consumerism/patient-centred; and rights/regulation.

PPI has been driven by greater calls for accountability and simultaneously a need for greater control by the consumer – even the phrase “consumer as king” (Bolton, 2002: p.129) has been used to describe the changing culture in healthcare. In some ways, healthcare has

gone through a “commodification” process (Sturgeon, 2014: p.405). But the assumption that organisations and Governments appear to have made is that a greater patient and public voice will ensure organisations are both accountable for their actions, and that patient choice is exercised to drive up quality. This assumption has been challenged, as Government policies and initiatives are based on ideology (Florin & Dixon, 2004; McEvoy et al., 2008). As we have seen from the recent scandal of Mid-Staffordshire NHS Foundation Trust failings (Francis, 2013), mechanisms put in place by successive Governments do not appear to be working, and implementation of such policies varies considerably in practice (Veronesi & Keasey, 2015). Martin (2009) describes the gap between the democratic ideal of these policies and the realities of the difficulties of realising the public’s voice (see quote below).

“every attempt at generating robust public involvement mechanisms is doomed to fall short of the deliberative-democratic ideal in some way: perfect representation of the full range of views and values across society, and the elimination of power from debates to achieve rational consensus, are ideals to be aspired to rather than fully realizable objectives” (p.130).

The historical context described in the previous sections presents the development of and changes to PPI in the UK. There have been various drivers – a rise in demands for democracy, calls to drive up efficiency and quality of services, and the need to make services more accountable. These drivers appear to be important factors to consider in developing our understanding of PPI now and in the future. The history of PPI has also highlighted the ongoing tensions between top-down and bottom-up management, as well as the tensions between collectivism and individualism. As such, it is now pertinent to move on to exploring the roles and perceptions of key stakeholders. The following sections explore the challenges of obtaining a ‘representative’ voice in response to these political agendas.

1.2. Representation: ‘Unrepresentative’ voices and the phenomenon of ‘professionalisation’

The following sections examine two key and frequent issues reported in the literature of the ‘problem’ of unrepresentative participants, and the phenomenon of ‘professionalisation’. As already described, the Government have repeatedly put a renewed focus on the agenda of PPI in healthcare. But there are claims in the literature that those who participate in these methods of PPI are often part of an ‘in crowd’ of people whom are already connected with services. This can mean exclusion of minority and vulnerable groups. They are also argued to be ‘unrepresentative’ of ‘typical’ patients because, not only are they from an already associated group of people, they are also homogenous in their characteristics (white, middle-class, well-educated, etc.) By claiming that these individuals are ‘unrepresentative’, professionals are potentially able to undermine their contributions and maintain a position of power over decision-making processes.

1.2.1. Representation and ‘the usual suspects’

There are numerous references in the literature to the ‘problem’ of representativeness and the recruitment of ‘the usual suspects’ (Barnes et al., 2006; Beresford, 2010; Daykin et al., 2004; Felton & Stickley, 2004; Gustafsson & Driver, 2005; Martin, 2008a, 2008b; Pickard & Smith, 2001; Rutter et al., 2004). Many professionals and decision-makers report that people who get involved are not representative of the general population or their ‘typical’ patients and service users, as they are usually white, middle-class, well-educated, and at retirement age (Barnes et al., 2006; Hudson, 2015; Learmonth et al., 2008; Martin, 2008a, 2008b; Masters et al., 2002; Renedo & Marston, 2015c; Tait & Lester, 2005; Thompson et al., 2014). Indeed, sometimes the laypeople themselves acknowledge they are not ‘representative’ (Martin, 2008a). However, some have found that the argument about representativeness presented by professionals is unnecessarily detrimental to the service user/lay perspective (Costello & Horne, 2001; Donaldson et al., 2007).

Furthermore, numerous studies have found that the people who are consulted about service developments tend to be those already attributed to user groups and representative organisations (Anton et al., 2007; Barnes et al., 2003; Barnes, 2005; Barnes et al., 2006; Beresford, 2010; Evans et al., 2013; Kearney, 2004; Légaré et al., 2011; Lowndes et al., 2001b; Martin, 2008a; Pickard & Smith, 2001; Rose et al., 2010). This exacerbates the

complaint many people have about the usual suspects participating – the views of other groups are either not heard or not sought, or take second place to the views of those that are part of the ‘in crowd’ (Anton et al., 2007; Barnes, 2005; Beresford, 2010; Martin, 2008a). These issues potentially present significant barriers for other individuals to become involved, and this further marginalises minority groups (de Frietas & Martin, 2015).

Hogg (2007) points out that if organisations wish to base representation on the actual users of healthcare services, then older people and children would need to be represented more than other groups. Hogg further highlights the question of how many patients or public members should you recruit to committees and forums to make them representative. Any guidance that offers suggested numbers may simply be arbitrary figures and may be unachievable. Hogg (2007) cites that the CPPIH recommended that Patient Forums have a minimum of 15 members, but in a 2004 survey, only 50 forums (of over 150) had at least 15 members due to recruitment difficulties.

Some have also found that the type of person who typically becomes involved in service developments tends to have activist attributes and are motivated by feelings of injustice and oppression (Barnes et al., 2006; Beresford, 2010) (motivations will be returned to in section 1.3.1.). Professionals sometimes report being wary of certain participants because they ‘bring their own agendas’, are jaded by their own experiences and force their views on others (Bovenkamp & Zuiderent-Jarek, 2013; Barnes et al., 2006; Rutter et al., 2004). For example, in an ethnographic study of a patient council by Brooks (2008), nursing staff had negative reactions to patient council members when they detailed personal experiences – they were silent or made verbal indications to ‘move on’ with the agenda. They reported feeling that patients’ own personal stories and experiences were irrelevant to discussions. As one nurse stated, “A lot of them come with their personal experiences: they cannot put them behind them and constantly interrupt...and yet in a professional setting people have to put all their personal stuff behind them, don’t they?” (p.8). But as one patient councillor in the study put it “The only thing we’ve got to bring to it [is] our own experiences.” (p.8)

Interestingly, there are very few studies that explicitly describe how patients/laypeople have been recruited to the activity being studied. This may simply be because the authors were not privy to information about the recruitment process. However, as many have

complained about a lack of representativeness of participants, exploring recruitment methods of organisations seems a logical way of understanding why participants are deemed unrepresentative. In the example of patient involvement in education, Jha et al. (2009) found that, of 47 articles on the topic, only 21 clearly described the recruitment process, and a further 17 briefly described recruitment with little detail. Légaré et al. (2011) also found a lack of reporting of recruitment methods in a review of the literature on PPI in guidance development.

An intriguing study by Lehoux et al. (2012) studied a genetics policy network in Canada that set out to actively avoid recruiting participants with significant interest in the topic, and instead focus on the ‘disinterested’ perspective – that is the perspective of ‘ordinary’ citizens. Four citizens were recruited through a “meticulous” (p.1845) recruitment process. The members of the network (which included health professionals and researchers) excluded anyone affiliated with any organisation in the field of genetics, or anyone with a health profession background. Their goal in doing so was to recruit citizens who could contribute to deliberation processes with a disinterested “rationality” (p.1845). The network was studied for four years and the profiles of these individuals were examined. Interestingly, at least one of the participants appeared to go through what could be termed a ‘professionalisation’ process over time (as will be described in more depth in the next section), in that they developed an in-depth knowledge and interest in genetics. This suggests that, even if an individual begins a process as a ‘disinterested’ participant, the changes they go through as part of their participation leads to them becoming ‘unrepresentative’.

1.2.2. Professionalisation of service users/laypeople

In addition to the representativeness argument, there is a phenomenon highlighted in the literature of ‘professionalisation’. This phenomenon refers to the process of change participants go through when participating in committees, task groups, projects, etc. Many academics have found that participants transform into confident, articulate, and assertive individuals (Beresford, 2010; El Enany et al., 2013; Ives et al., 2012; Learmonth et al., 2008). This process has been termed as professionalisation, as participants begin to show attributes usually associated with professionals. To professionals, patients whom become professionalised no longer represent to them a ‘typical’ patient.

There is also the issue of how qualified the typical patient or layperson is to contribute to major service decisions. The professionals, having had years of training, qualifications, and experience, are arguably more qualified to make important decisions about, not only an individual's care, but service provision on the whole. Professionals usually also have a greater understanding of the wider context – evidence-based practice from the latest research, knowledge of the typical needs of the local population, and the financial costs of service developments (Callaghan & Wistow, 2006; Hunter et al., 2016). This information is not something patients are usually privy to. This potentially gives professionals' views greater weight and, ultimately, greater power.

In the case of PPI in research, Ives et al. (2012) point to a paradox at play – participants need to be trained in research methods to contribute effectively to research design, but by doing so, become professionalised and no longer represent a lay perspective. Learmonth et al. (2008) point to the same paradox in the wider scope of the patients' voice in healthcare – the 'Catch 22' of needing to be 'ordinary' to be representative of the general public, but that being 'ordinary' equates to less effective participation (e.g. by having time constraints and other priorities in their lives). Furthermore, in the example of patient involvement in guideline development, Bovenkamp & Zuiderent-Jarek (2013) suggest the patient perspective does not fit well with evidence-based medicine, rendering increased knowledge of participants necessary. But that increased knowledge in turn renders the patient perspective no longer representative. Ives et al. (2012) also suggest that, whilst training patients in research methods does not remove their patient perspective, it makes their perspective "tamed" (p.183) to be more "congruous with that of the professional researcher" (p.183).

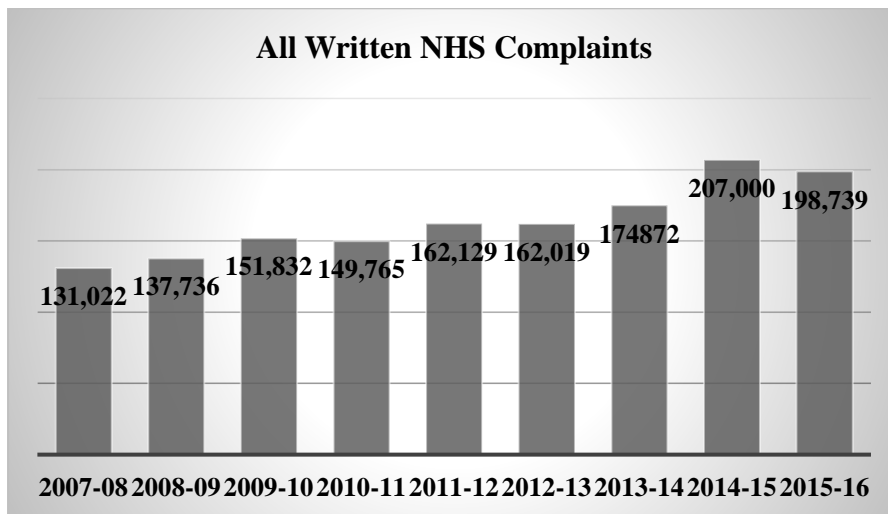
However, a key argument of those who support the patient's perspective, regardless of professionalisation or not, is that patients have a form of knowledge professionals do not possess – experiential knowledge (Attree et al., 2010; Bovenkamp & Zuiderent-Jarek, 2013; Bradshaw, 2008; Glasby & Beresford, 2006; Lopes et al., 2015; MacDonald & Taylor-Gooby, 2010; Tait & Lester, 2005). When it comes to the realities of care, access to services and what it's like to suffer from an illness, no one understands this better than patients (Attree et al., 2010; Hudson; 2015; MacDonald & Taylor-Gooby, 2010). Therefore, what patients can bring to a service development project is their 'story' of the patient journey.

Typical examples of where experiential knowledge can be valuable include issues such as timings of appointments, physical facilities, transport, access, what information is given to patients and when, and management of symptoms and side effects. Furthermore, the patient viewpoint can offer insight into the ‘relational’ aspects of care, such as compassion and empathy (Hudson, 2015). As a result of the differing perspective point, patients can offer up solutions professionals may not have thought of (Attree et al., 2010; Bovenkamp & Zuiderent-Jarek, 2015). In addition, Lopes et al. (2015) note that patient representatives tend to focus more on the patient as a whole, advising decision-makers to take a more holistic approach, based on their experiences of illness rather than merely the clinical elements of care. And whilst most of the perceived value of the patient perspective is in their lived experiences of illness, on occasion they can also offer insights into clinical decisions. For example, Bovenkamp & Zuiderent-Jarek (2013) found that professionals assumed generic prescribing would be better for Parkinson’s disease patients, but this was challenged by the patients involved.

1.2.3. A nation of complainers

As will be described in more depth in section 1.4.1., patients and the public can express their views in a number of ways. The issues already discussed above relate more to regular forums and committees, but there are many other ways in which patients and the public can have a voice. In an age of consumerism, the public are demanding more from services, and as such, complaining when services do not meet their expectations. Formal complaints against NHS organisations have been increasing steadily for several years, but have peaked in recent years as shown in Figure 3 from figures from the Health & Social Care Information Centre (HSCIC, NHS Digital, 2016). This shows a clear shift in the way the public view services – they are exercising their rights as a consumer to put forward their views and demand more from services.

Figure 3: NHS Complaints data 2007-2016 (Source: NHS Digital, 2016)²



It could be argued that the number of complaints illustrates a declining quality of care (though many other measures suggest otherwise, such as declining mortality rates, increasing cancer survival rates, and lower hospital-acquired infection rates, source: Office for National Statistics). But there are estimates that around 30-40% of complaints are not upheld (NHS Digital, 2016), prompting the question are expectations of the NHS now unrealistic? An article by Ellins (2011) discussing the implications of further NHS reforms on the future of PPI in the NHS pointed out this very issue – younger generations in particular do seem to have higher expectations.

Consumers are also now Tweeting about and reviewing healthcare services online. For example, patients can review any NHS provider on the NHS Choices website. Many healthcare organisations now have a presence on social media to connect with their service users and provide another accessible channel of communication. This more recent change in the communication between the public and public services has been called ‘crowd-sourcing’ of opinions (Adams, 2011; Bertot et al., 2012). It provides organisations with real-time snapshots of their service users’ views. Indeed, even back in 2002, McIvor et al. pointed out the opportunities internet technologies offered organisations in achieving transparency, as did Ancarani (2005) and more recently Bertot et al. (2012). The differing methods of communication between patients and the public, and services will be returned to in section

² NB. Mandatory publication of the number of complaints each organisation receives was only introduced in 2011, so previous years’ data is not complete for comparison and is, therefore, based on estimates by HSCIC.

1.4.1. What the increasing number of complaints might indicate is consumers are more demanding of services, perhaps having now unrealistic expectations.

1.2.4. Summary

Whatever one's viewpoint, the arguments presented in the previous sections demonstrate that there is tension between professional and layperson roles in PPI, and the legitimacy of their views. Role identity is potentially a key factor here – professionals may feel that their traditional role of being an 'expert' is threatened by laypeople, particularly by those who become professionalised and more assertive. Equally, how the layperson identifies themselves can create tension and challenge. If they continuously behave as a more passive typical patient, their viewpoint is potentially quashed, regardless of how valid it may be, because professionals will maintain their powerful 'expert' position. If they become more knowledgeable, articulate, and assertive in their arguments, professionals may feel threatened and undermine the laypersons' view by deeming them to be no longer representative. In both cases, professionals maintain power, and the laypersons' views and involvement has potentially little impact.

As such, it is pertinent to understand in depth the individual perspectives of stakeholders involved in PPI activities. Understanding these perceptions can aid our understanding of why the debates regarding representativeness and the issue of professionalisation persist. These individual identities and perceptions, and concepts around power-sharing, will be discussed in the next few sections, and were key considerations made in the present study.

1.3. The individual perspective: Motivations, identity, and power conflicts

The previous sections have already alluded to some of the identity issues that are often at play in PPI, given that the process of PPI brings together stakeholders with very different viewpoints and backgrounds. This section further discusses identity issues, and describes the motivations for why people get involved in PPI. The motivations of patients and the public are well documented in the literature – they are varied, but generally tend to originate from a negative experience of services. Of less note are the motivations of professionals, though there is much research on the purposes of PPI as viewed by healthcare professionals and managers. The next few sections also discuss how roles of individuals are defined and whether power sharing is possible.

1.3.1. Motivations for involvement – the layperson perspective

Research that has explored individual perspectives and experiences of PPI suggests that people who get involved are often motivated by a desire to help improve healthcare services based on their own or loved ones' negative experiences (Anderson et al., 2006; Barnes et al., 2006; Cotterell et al., 2010; Donaldson et al., 2007; Freitas, 2015; Lowndes et al., 2001a, 2001b; Rutter et al., 2004). They are seeking justice and change and, in doing so, prevent others from having the same negative experiences. However, poor experiences do not motivate all participants – others have received excellent care and treatment, and want to 'pay back' for those services (Cotterell et al., 2010; Thompson et al., 2014).

Participants can identify themselves as advocates and representatives of others whom they believe to have either been affected by the same issues, or will experience them in the future (Donaldson et al., 2007; Lewis, 2012). Barnes et al. (2006) identified six types of motivation for laypeople in their study of public participation, all of which include an element of wanting to improve services. These six types of motivation were “commitment to a [geographical] area”, “a religious commitment”, “commitment to a cause”, “being representative of a people”, “lifelong commitment to various causes”, and “commitments derived from personal experiences of difference, exclusion or disadvantage” (p.197).

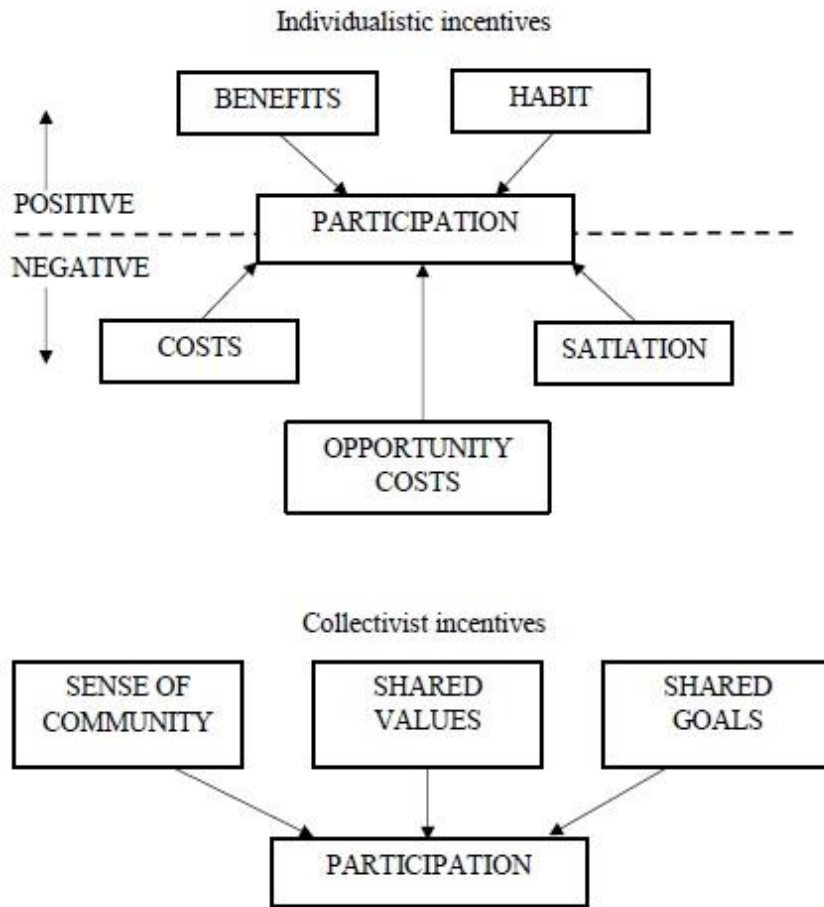
Furthermore, as would be expected given the motivations and past experiences of these individuals, participants are generally very passionate and have strong emotional connections with the subject matter. Lewis (2012) points out the significant 'emotional labour'

participants work through during PPI activities; the kind of emotional labour Bolton (2002) noted in nurses since the rise of consumerism. This is potentially something that has been under-appreciated by professionals and organisations when involving patients and the public. Indeed, Cotterell et al. (2010) found that cancer patients felt professionals did not value their emotional experiences and they found it difficult to hold back emotions during conversations. One patient is quoted saying:

“it’s difficult to engage in the conversation unemotionally on something that has had such a profound impact on you. It means you are on a different footing to the other people in the room” (p.165).

Another study specifically on motivations of laypeople has drawn upon the Mutual Incentives Theory to examine why laypeople get involved in public services (Simmons & Birchall, 2005). Their study explored to what extent individuals are motivated by collective or individual issues (see Figure 4 for diagrams of the incentives identified). Again, individuals were more motivated when their experiences of services were negative. Interestingly, when respondents were asked about the costs of participating, most perceived there to be no costs and this was suggested to be indicative that they had put their focus away from individualistic concerns to collective ones. Furthermore, they reported personal benefits of participation as less important the more involved they got. Participants claimed they would still participate even without any personal benefits, placing more importance on collective ones. This contrasts with studies that have found participants are often incapable of setting aside their personal grievances and agendas (Barnes et al., 2006; Brooks, 2008; Rutter et al., 2004).

Figure 4: Individual and collective incentives in participation (Simmons & Birchall, 2005: p.266 and 268)



1.3.2. Motivations for involvement – the professional perspective

Interestingly, there is little reference in the literature to the personal motivations of professionals involved in PPI activities, likely because most research has focused on laypersons' views and perspectives, and/or specific PPI processes. However, there are some studies that have explored staff perceptions alongside the layperson perspective. Lightfoot & Sloper's (2003) study, for example, found that staff involved were motivated by wishes to know what patients think and design services around those perspectives, making them more attractive for future funding.

Barnes et al. (2006) also interviewed some public service officials alongside laypeople, and found that their motivations and backgrounds were markedly similar to the laypeople – some also even had a history of activism like the laypeople in the study. This presents an interesting dynamic in the relationships between laypeople and public services. Barnes et al.

(2006) suggested that some professionals appeared to be “allies” (p.200) of the laypeople. In another sense, professionals are also citizens, and sometimes patients themselves (Jordan & Court, 2010), so constructs of roles and identities in relation to PPI cannot simply be placed into homogenous ‘professional’ and ‘patient/service user’ groups.

Though most research into individual perspectives has focused on laypeople/patients’ motivations, other research has attempted to identify the purposes of PPI, as reported by health professionals and managers. Milewa et al. (2002) found that the most commonly cited purpose was quality improvement, but there were several other purposes too, including simply the pressure from Government (see Table 1 for full results). The purpose of PPI being defined as to improve the quality of services has been found elsewhere too (Anderson et al., 2002; Attree et al. 2010; Rowe & Shepherd, 2002). Rowe & Shepherd (2002) also found PPI can be used for public health purposes (health education and empowering people to look after themselves). It is important to note, however, that these reported purposes are not necessarily indicative of what motivates professionals personally.

Table 1: Reasons for Primary Care Group initiatives for public and patient involvement (Milewa et al., 2002: p.44.)

Reasons for initiatives in public and patient involvement	Frequency of reasons cited % (n)
To improve quality/responsiveness of healthcare	42.4 (122)
Pressure from Government	11.5 (33)
To increase transparency/accountability	11 (32)
To explain or justify prioritisation decisions	9 (26)
Pressure from public, patients, or society	8.7 (25)
To widen involvement in prioritisation decisions	5.9 (17)
Other reasons	11.5 (33)

Solbjør & Steinsbekk (2011) also found that the value health professionals reported seeing in involving patients was obtaining access to their knowledge, which differed from their own (experiential versus technical/medical knowledge). Furthermore, Richardson et al. (2005) found that there were generally five purposes of PPI in the case of cancer networks: providing a ‘voice’ for service users, working in partnership with other parties, ensuring service users were involved in decision making, influencing policy and services, and

improving patient care. Though, again, it is worth noting these reasons are not necessarily indicative of what motivates professionals on an individual level.

Rise et al. (2011) interviewed patient and public representatives, and managers and health professionals in Norway about PPI experiences. They found that, whilst there were some similarities in their perceptions of why PPI was important (e.g. mutual respect), each group reported different purposes behind these characteristics. Table 2 summarises the key differences in perspectives. Rise et al. (2011) noted that, interestingly, both groups were concerned the other group wanted sole decision-making influence. Note in the table that service users reported sometimes *needing* to be excluded from decisions, whilst providers reported the service users had to choose from “professionally sound options”. This suggests that professionals ultimately hold more power in the decision-making process.

Table 2: Analytic categories from interviews (Rise et al., 2011: p.269)

Service users	Providers
Being heard and taken seriously	Providing knowledge and information
Dialogue	A part of the treatment
Taking part in the decisions	A given/self-evident/implied
Not being overruled	The relationship between health personnel and user
Voicing needs and wishes	The users decide or do not want to decide
Human worth and respect	Users’ influence on the treatment
Receiving explanations and information	The users’ rights
Contributing to treatment and controlling your own situation	Coercion excludes participation
Being exempt from decisions when needed	Users have to choose between professionally sound options
Being trusted and believed	Respecting, recognising, and taking the user seriously

1.3.3. Defining roles and identity

Defining roles with regards to PPI can be a considerably important factor in influencing the process and outcomes of PPI. This is not just about how one defines their own role, but also how people define one another’s roles. Where there are differing interpretations of role definitions, it is possible for conflicts to arise. Professionals often report being unclear about

the role purpose of laypeople, patients, and service users (Buck et al., 2014; Felton & Stickley, 2004; Hogg & Williamson, 2001; Renedo & Marston, 2011), and indeed laypeople themselves can be unclear (Costello & Horne, 2001; Pickard & Smith, 2001). A lack of clear definition of their role has led participants to feel the need to justify their contributions (Hitchen et al., 2011). It has also often been witnessed that terms for roles are used interchangeably (such as ‘service user’ and ‘patient’), further adding to a lack of clarity (Baggott, 2005; Dexter et al., 2012). Jordan & Court (2010) attempt to highlight the differing origins of the various terms used, as summarised in Table 3. They argue it could be “just a matter of semantics” (p.559), but the origins and applications of the terms suggest very different role positions that are rooted in fundamentally different ideologies.

Furthermore, as already alluded to, it is important to note that ‘patients’ are not a homogenous group. There are different sub-groups, whom will all have differing role identities and perspectives. Government policies and guidance on PPI are inherently flawed by treating ‘patients’ and the ‘public’ as entirely homogenous groups (Learmonth et al., 2008; Martin, 2009). Indeed, Martin (2009) found that, even within a seemingly homogenous group of participants in a programme to improve cancer care pathways, there were a diverse range of perspectives and contributions. Smith et al. (2009) found that there were considerable differences in interpretations of roles by laypeople from differing educational attainment levels. Those with higher education and literacy levels perceived their role as one of sharing decision-making with professionals. In contrast, those of lower education and literacy levels viewed their role to be one of supporting the recommendations of health professionals.

A study by Dexter et al. (2012) showed how Clinical Psychologists viewed children as “in need of protection”, “developing beings”, and “powerless” (all p.252) in the context of PPI (though they did acknowledge the “unique” (p.256) perspective they offer). Where children were viewed as passive subordinates, this led to limited participation. Interestingly, those professionals who positioned children as ‘consultants’ seemed to involve them to a greater extent than those who positioned children as passive patients. This demonstrates how the role perceptions of one group have the potential to influence the role of another.

Table 3: Role definitions and their origins (Source: Jordan & Court, 2010)

Term	Origin/definition
Patient	Derived from Latin word <i>patiens</i> and is defined as ‘one who is under medical or surgical treatment...enduring pain, trouble, affliction, hardship with fortitude, calmness, or quiet submission’. The language strongly suggests a passive and subservient position.
Client	Derived from Latin word <i>cliens</i> and is defined as ‘one who employs or seeks advice from a professional advisor’. Whilst this language puts more ownership on the individual, it still also suggests a level of subservience.
Consumer	Originates from ‘neo-classical economics’, characterising individuals as increasingly acquiring power and influence – but this concept is often rejected due to its individualistic concept that does not marry up with healthcare services (collective delivery).
Activist	Defined as groups of individuals who protest various aspects of healthcare. This term potentially implies patients themselves are not strong enough to raise concerns.
Advocate	Defined as individuals who ‘represent’ a group of people (usually grouped by a common issue such as a specific medical condition) to raise concerns on their behalf. This term has the same connotations about placing a patient as ‘weak’ as the term ‘activist’ does.
Layperson	Derived from Anglo-French term <i>lai</i> referring originally to people who were not members of the clergy, but which now generally refers to those who are not of a profession. This term is arguable less controversial than the others above, but in reality these individuals are not necessarily devoid of professional characteristics, therefore making the term inadequate.

In the case of mental health service users, they can be seen by professionals as incapable of participating because of the nature of their condition, in that they can be irrational and even irresponsible (Felton & Stickley, 2004; Rush, 2004). Professionals also cited practical problems with bringing mental health service users into the classroom setting, because they may struggle to cope with the demands of the work, and their sometimes-unpredictable behaviour could disrupt teaching (Felton & Sitckley, 2004). Again, this highlights how the perceptions of one group can potentially inhibit another. Lammers & Happell (2003) stress that mental health service users should also not be treated as a homogenous group and their individual needs should be addressed to enable participation.

When exploring professionals' identity interpretations of lay participants, Renedo & Marston (2011) point out the contradictory definitions and the tensions within these definitions. They identified five discourses of lay participation from health professionals: 1) discourses of epistemology; 2) discourses of civic engagement; 3) discourses of pragmatism; 4) discourses of democratic equality; and 5) discourses of reflexivity. These discourses "played out in diverse and opposing representations of identity" (p.272). The lay participant was framed "simultaneously as a technocrat patient, self-interested political agent, and institutionalised reflexive citizen" (p.272). These conflicting and paradoxical constructions of the lay participants' identity led to limiting the lay participants' role in practice. The following quote from a layperson involved in the same study sums up the lay participant's struggle:

"being an involvee is about struggling first to assert a legitimate identity as a public participant, second to 'survive' as a lone outsider and a minority in complex expert-systems, third to exercise agency when having to adapt to institutional top-down forms of PPI, and fourth to cope with threats to lay identities and derogated common-sense knowledge." (p.278)

There are also conflicts between participants as 'patients/service users' and 'citizens'. Returning to Lehoux et al.'s (2012) study of a genetics network described in section 1.2.1., participants identified themselves in numerous ways and have various "biographical resources" (p.1845) (skills, beliefs, etc.). Four citizen participants in the genetics network were profiled, summarising their characteristics and concepts of themselves as citizens. There were subtly different perceptions of their view of what a citizen is, and their attempts to be a citizen in the network varied. Two identified citizenship as going beyond individual needs, another claimed it "sits uncomfortably between the rise of individualism and the search for the common good", and the other deemed it to be "politically dubious" (all quotes from Table 1 on p.1848). One of the participants eventually withdrew from participating due to her struggles to "make space for the citizens' voice" (p.1848). Unfortunately, what this study does not highlight is how the other members, as professionals, perceived the roles of these individuals, which could have shed further light on the conflicts. The findings from this study were also echoed by Frederiksson & Tritter (2016), who found that the fundamentally different perspectives of 'patients' and the 'public' (individual versus collective perspectives)

should always be treated as separate and patients should not be treated as a proxy for the public.

Patients, service users, and laypeople can identify themselves using a wide range of labels: 'patient', 'consumer', 'advocate', 'service user', and 'citizen'. But a study by Litva et al. (2009) also suggests another less cited identity: one of "overseer" (p.85). In their study of laypersons' views of their roles in clinical governance, the common identities of 'advocate', 'citizen', and 'consumer' were identified, with the addition of 'overseer'. In practice, this meant overseeing the process of decision-making by professionals, and challenging assertions and the information upon which decisions were made. It also involved overseeing the process to ensure the interests of service users were considered. Pickard & Smith (2001) found that laypeople see their role as keeping local people informed (information sharing); representing the views of local people; representing the views of service users; and representing the views of specific groups, such as homeless people. But there was a lack of clearly defined roles for laypeople from professionals, and so they arguably established their own personally-defined roles.

In addition, when Crocker et al. (2016) interviewed participants in health research about how they viewed the impact of their role, six conceptualisations of their roles were identified: the 'expert in lived experiences' (participants can contribute to acceptability and meaningfulness of the research), the 'creative outsider' (participants contribute 'outside the box' problem-solving), the 'free challenger' (participants can challenge the researchers freely), the 'bridger' (participants bridge the gap between patients and researchers, making research more relevant), the 'motivator' (participants help motivate researchers with their enthusiasm), and the 'passive presence' (their mere presence makes researchers think differently). This demonstrates the diverse interpretations by lay participants about how they identify their role.

Furthermore, research by Renedo & Marston (2015c) showed how participants feel they must navigate complex healthcare structures and processes, and gather significant knowledge about the organisation, to enable meaningful participation in decision-making (further demonstration of the professionalisation process referred to in section 1.2.2.). They also describe themselves as a 'guest' in the organisation, as professionals generally decided on the venue and the agenda of the activity, and designed the materials and methods used.

Renedo & Marston argue that these artefacts are symbolic of the professionals' power maintenance, and participants described multiple ways in which they adopted behaviours to 'fit' in with the professionals. One participant in the study even used the phrases "beat the system" and "plot your way through it" (both p.7) in describing their own navigating behaviours.

1.3.4. Is power sharing in PPI possible?

The notion of 'power' in relationships (particularly relationships between healthcare professionals and patients/laypeople), and how it manifests in behaviours and dialogue, is something that is frequently debated. A rather simplistic view of power in relationships assumes that one party dominates the other – that power is a "finite resource" that is acquired by one party at the expense of another (Weber, 1986; as cited in Callaghan & Wistow, 2006: p.586). Others would argue that power can be shared where both parties or groups have legitimate claims to power over decision-making. Callaghan & Wistow (2006) discuss the roles of the 'public' and 'citizens', and their legitimacy in claims to power. They describe how "consumers speak with the authority of service users...with a legitimate interest in provision on a personal basis...By contrast, the role of citizen is based on the legitimacy of legal, political and social membership of the community" (p.585). The contrast here is really concerned with individual voices (consumers) versus collective voices (citizens).

Callaghan & Wistow's (2006) observations of, and interviews with, professionals and laypeople involved in two PCGs showed that, whilst PPI overall was treated as a good thing by all parties, there were examples of a lack of yielding of power by professionals. Professionals would make suggestions that views of the public might not have equal weight to those of professionals, because professionals have "inside information" (p.591). Professionals sometimes took steps to set the agenda themselves to avoid conflicts; something also noted by Barnes et al. (2007), Rutter et al. (2004) and Matthews (2001). Callaghan & Wistow (2006) suggested that these are not necessarily actions "actively intended to exclude" (p.590), but that, instead, professionals are so constrained by "dominant and accepted ways of thinking" (p.590) in institutions, they are unable to yield power. If this is the case, then the sharing of power is not possible without changes to those established ways of thinking. Furthermore, Milewa et al. (2002) found that there was an "enduring influence of healthcare managers and professionals in comparison to that of patients and citizens" (p.807), indicative of established and institutionalised behaviours. Nilsen et al.

(2010) similarly concluded that health professionals are “socialised and organised to view themselves as authorities” (p.4).

Hodge (2005) argues that these behaviours are an *explicit* and conscious exertion of authority and power, rather than unconscious behaviours rooted in the norms of the professional environment. There are also examples in the literature of professionals reporting fearing PPI “eroded” (Felton & Stickley, 2004: p.94) away their role, or that it was an “infringement” (Attree et al., 2010: p.54) upon their role. As such, they will potentially make attempts to limit the involvement of patients and the public, such as through the agenda-setting behaviours already mentioned. Furthermore, the user perspective has been found to be used to legitimise the professional’s position (Donaldson et al., 2007; Hunter et al., 2016; Solbjør & Steinsbekk; 2011; Weale, 2016). Another study by Daykin et al. (2004) also found that professionals could not meet a consensus on the statement “users should be involved in decisions about all aspects of cancer services” (p.286). They suggested this potentially shows how professionals attempt to limit the remit of PPI. Solbjør & Steinsbekk (2011) found that one solution for achieving power-sharing was for professionals and patients to “teach each other about the kind of knowledge that each possessed” (p.147), which helped them appreciate one another’s perspectives better.

In a review of the literature on PPI in health priority-setting, Hunter et al. (2016) point out that the defined role of patients and the public is limited, as set by professionals, further supporting the notion that professionals maintain ultimate power. They found that the role of patients and the public is restricted in several ways: 1) design (participants merely approve or are assumed to accept the professionals’ designs of a service); 2) scope of input (participants are restricted in their involvement in practical terms); 3) extent of influence (participants’ views are weighed up against those of professionals); and 4) modification (potentially manipulating participants’ views to meet or legitimise professionals’ views) (p.801).

Some would argue that power sharing is not possible because of the opposing ideologies from which service users/patients and professionals come from, causing conflicts to arise (Beresford, 2010; Carr, 2007; Fotaki, 2010). On the one hand, there is the managerialist approach concerned with the ‘top-down’ interests of the state; and on the other, the democratic approach concerned with the ‘bottom-up’ interests of individuals (Beresford, 2010). The rhetoric of Government policies contains discourses about ‘partnership’ and

putting more power in the hands of patients and the public (see Hui & Stickley, 2007, for example), but the realities of PPI prevent meaningful implementation of that rhetoric. Furthermore, Evans et al. (2013) point to the different “worlds they [professionals and patients] inhabit” (p.511) as a possible reason for a lack of power-sharing. Patients and service users are outsiders, with a physical distance from health services, whereas health professionals inhabit the healthcare setting continuously, having so-called ‘corridor conversations’ and other informal interactions with each other.

Having said this, a study by Locock et al. (2016) focusing on PPI in research found that power relations did begin to shift over time. Interviews with patients, carers and laypeople involved in research highlighted the differing knowledge that professionals and patients and laypeople hold. As already described in previous sections, other studies point to the different types of knowledge and experience professionals and patients have and how this can lead to conflict. It has been argued that the knowledge professionals have as the ‘expert’ gives them greater power because they have higher ‘symbolic capital’ (status and respect) than patients. Locock et al.’s (2016) study highlighted that patients and carers have different symbolic capital through their lived experiences of illness and additional specific knowledge of their condition. However, this symbolic capital can be ‘unstable’ in that, the more involvement they have in research, the more they develop other knowledge (similar to the phenomenon of professionalisation referred to earlier). Locock et al. (2016) argue that, although their social capital is unstable, over time the power gradually shifts as the professionals gain greater appreciation of the symbolic capital patients have.

1.3.5. Summary

Given the complexities of the relationships between, and identities of, professionals and patients and laypeople, it seems that power sharing over decisions may not be possible. It appears that PPI can serve to merely ‘legitimise’ professionals’ views and support their decision-making powers because of the limits of the role of laypeople. The experiential knowledge patients have is also often in conflict with the technical and medical knowledge of professionals, resulting in the lay perspective being undermined. Ives et al. (2012) argue that we may have to accept that a “truly cooperative model of PPI” (p.183) may not be achievable because it is “an ideal that can never truly flourish, simply because the concept is not internally coherent” (p.183). Instead, in the example of PPI in research, Ives et al. point out that there are areas of research where patients can have a more meaningful contribution

without the ‘paradox’ of the professionalised lay perspective – the funding, reviewing and dissemination stages of research that do not require specialist knowledge like the design, analysis, and reporting stages of research. Applying this logic to other areas of health, it may be that patients’ involvement should be in aspects of service developments that do not require specialist knowledge. This is arguably a pragmatic solution to the problems discussed in the previous sections.

Ives et al.’s (2012) suggestion to determine practical application of PPI points to the potential disconnect Martin (2009) highlighted (see section 1.1.5.) between the ideals of political policy and the practicalities of its application. It is now pertinent to explore in depth the methods of PPI utilised, why they are chosen, and their benefits and limitations. Only by understanding the practical application of PPI can a complete picture be obtained. As such, what follows in the next few sections are a discussion of the methods, barriers, facilitating factors, and impact of PPI.

1.4. The pragmatist perspective: Methods, practical barriers and facilitating factors

The literature on PPI highlights a wide range of methods, from small focus groups to formal committees. PPI also features in a variety of areas of healthcare – mental health, children’s services, and community services, as well as other areas such as governance, medical and nursing education, and health and medical research. There is also a wide range of barriers and facilitating factors cited in the literature, including individual factors such as skills and confidence, organisational factors such as bureaucracy, and practicalities such as venue accessibility. The following sections describe the multiple methods, barriers and facilitating factors before discussing the impact of PPI.

1.4.1. The variety of methods

A range of methods of PPI have been employed by healthcare organisations, local authorities, and Government agencies to engage with and involve patients and the public (Anderson et al., 2002; Alborz et al., 2002; Crawford et al., 2002; Lowndes et al., 2001a; Milewa et al., 2002; Mockford et al. 2012; Nilsen et al., 2010). Equally numerous initiatives, policies and structures have been put in place to enable participation, (see sections 1.1.1-2), though this has been described as complex and incoherent (Baggott, 2005), and in disarray (Bradshaw, 2008). Broadly, methods of PPI can be categorised similarly to research methods into qualitative and quantitative methods (Munro, 2008), and Snyder & Engström (2016) identified three forms of PPI in a review of the literature: patient involvement in decision-making; patient involvement in healthcare delivery; and patient involvement in the development of healthcare.

In a survey of mental health providers and service user groups, Crawford et al. (2003) identified a wide range of methods being employed to involve service users. Like other research has found, a range of methods were utilised. Methods included involving patients in assessing the quality of services, lay membership of Trust meetings and committees, public attendance at Board meetings, and involving patients in assessing staff training programmes. Furthermore, their survey found that 80% of service user groups were not satisfied with current arrangements for involvement and 28% felt their Trust was not committed to involvement. In a survey of PCTs and PCGs by Alborz et al. (2002), 87% consulted CHCs, 75% held public meetings, and 67% consulted local groups. Milewa et al. (2002) also found a

similar range of methods, from surveys, to membership on committees, to attending voluntary sector and community support groups.

One of the most popular methods is patient surveys and questionnaires for obtaining feedback about services (Boiko et al., 2014; Forbat et al., 2009; Fudge et al., 2008; Lightfoot & Sloper, 2003; Munro, 2008.) All NHS Trusts across the UK are also required to take part in a range of national surveys. The surveys ask a range of questions concerned with how the person was treated by staff, how satisfied they were with treatment, and how satisfied they were with the information they received. Results from national surveys are published online, and the National Inpatient Survey became an incentivised target as part of the Commissioning for Quality & Innovation (CQUIN) Payment Framework (DoH, 2008).

These quantitative methods have, however, received criticism. Many of the questionnaires providers issue themselves internally have not gone through the type of scrutiny a validated questionnaire would have to go through before being used for academic research (Munro, 2008). They often haven't gone through a pilot process either. Questions can be leading and not objective, causing some to suggest that the decision makers are merely seeking approval to decisions they have already made (Alborz et al., 2002; Day, 2008). In addition, research by Boiko et al. (2014) highlighted that professionals interpreting results of surveys question their validity. Despite criticisms, however, they remain a popular method of gaining feedback from patients and the public. Qualitative methods of engaging with patients and the public are often ad-hoc. Focus groups and patient interviews are sometimes used for a specific purpose, as part of a service improvement project or to discuss a particular issue (Munro, 2008).

Other more formal methods are used such as forums, committees, and citizens juries (Barnes 2005; Barnes et al., 2004; Hudson, 2015; Matthews, 2001; Parkinson, 2004; Pickard & Smith, 2001; Street et al., 2014; Whitty et al., 2014). Many patient and lay representatives also attend various committees and panels sponsored by either a healthcare provider or by the local commissioning organisation, or by a patient representative organisation. These methods of PPI can range from very formal exchanges at committees to less formal interest group meetings (Abelson et al., 2003; Solbjør & Steinsbekk, 2011). There have been a range of issues identified with this form of PPI, however, such as a lack of representativeness (i.e. having just one representative on a committee), unclear purpose (i.e. who they represent,

what their role is, how involved they should be in decisions, etc.), tokenism (i.e. lay representative only there because the organisation has been required to have one), and professionalisation (i.e. lay people begin to exert professional qualities) (Abelson et al., 2003; Felton & Stickley, 2004; Forrest et al., 2000; Fletcher, 2003; Pickard et al., 2002). These issues have already been discussed in sections 1.2.1-1.3.5.

Consultations are another method of PPI. Consultations are arguably the most formal of all methods, given they are a legal requirement for providers and commissioners when making significant service decisions (Health & Social Care Act 2001). A common reason for holding a consultation is the closure of a clinic or hospital, or the movement of a service to another location. Service leads and commissioners will draft a proposal which is then made publicly available for obtaining approval from the wider public. There is also usually a formal publicly-held event so decision-makers can take direct questions from the public. Respondents are asked to indicate if they agree with the proposal or not. Again, consultations have been criticised for being tokenistic and for leading people one way or another based on decisions that have effectively already been made (Alborz et al., 2002; Day, 2008; Thomas et al., 2010). As can be seen in Figure 5, which is an extract from a consultation leaflet, the questions appear to be very leading. The leaflet calls for participants to agree with their 'preferred option', and it presents many weaknesses for the option not favoured by decision makers.

In summary, Beresford (2010) suggests methods of PPI can be grouped into three categories: 1) consultative involvement (which is essentially information-gathering exercises); 2) deliberative structures (forums, committees, etc.); and 3) service user-controlled organisations (lobbyist/activist groups, service-user groups, charities, etc.). The key differences are the levels of representativeness (committees sometimes just have one individual whereas service user controlled organisations are all service users); the format and level of involvement in decision-making (consultative methods involve no sharing of decision-making); and differing drivers (organisation-driven versus service user-driven).

Figure 5: Extract from a consultation leaflet³

The options These are the options which we would like you to consider.

Option 1 Option 1 is urgent care at the current Walk-In Centre at [REDACTED]

<p>[REDACTED]</p>	<p>Strengths</p> <ul style="list-style-type: none"> • Location good for some people • Good clinical service • Will see anything • Open 24/7 • Patients returned to GP if appropriate 	<p>Weaknesses</p> <ul style="list-style-type: none"> • Location not good for some people • Some duplication with other services • Can't treat everything • Limited x-ray • No access to immediate blood test results or ultrasound • No beds for observation
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Option 2 Option 2 is urgent care provided at [REDACTED] Hospital in [REDACTED]

The preferred option

<p>[REDACTED]</p>	<p>Strengths</p> <ul style="list-style-type: none"> • Location good for some people • Good clinical service with potential increased access to specialists • Open 24/7 • Patients returned to GP if appropriate • Potential for observation beds • Access to on site ultrasound and potential for immediate blood test results • [REDACTED] GPs could use Walk-In Centre site • Avoiding duplication of x-ray facilities in the town (currently there are x-rays at [REDACTED] and [REDACTED] Hospital) 	<p>Weaknesses</p> <ul style="list-style-type: none"> • Can't treat everything • Location not good for some people
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Option 2 is our preferred option because of the additional diagnostic tests that would be available, and the potential for observation beds where people would sometimes be able to stay for observation rather than being transferred to [REDACTED] infirmary. In addition, there could be the potential for greater clinical support from other professionals running clinics and caring for patients in the wards. It would also help to further establish [REDACTED] Hospital as a treatment facility for local people.

10 [REDACTED] Clinical Commissioning Group | Managing urgent care in [REDACTED]

³ Leaflet has had parts redacted for anonymization

1.4.2. The increasing use of patient experience measures

Something that has increased in the last 10 years against the backdrop of consumerism is the focus on measuring patient experience for the purpose of informing quality improvements (Boiko et al., 2014; Boquiren et al., 2015; Mullen et al., 2011; Newman et al., 2004). Some might argue that patient experience measures like these are not actually PPI; however, as some studies have found (Alborz et al., 2002; Crawford et al., 2003; Milewa et al., 2002), organisations report utilising a range of methods of PPI, of which surveys is one, suggesting that practitioners view patient experience to be part of PPI.

Improving patient experience is a key government directive for healthcare organisations. Guidelines on patient experience (NICE, 2012) highlight five distinct areas organisations should focus on to give patients a good experience of care:

1. Knowing the patient as an individual – healthcare providers should “develop an understanding of the patient as an individual, including how the condition affects the person, and how the person’s circumstances and experiences affect their condition and treatment.” (p.8)
2. Essential requirements of care – five key aspects of care should be present: a) respect for the patient; b) patient concerns (handling sensitive issues such as end of life care); c) nutrition, pain management and personal needs; d) patient independence; and e) consent and capacity.
3. Tailoring healthcare services for each patient – four responsibilities of healthcare providers are cited: a) an individualised approach to services; b) patient views and preferences; c) involvement of family members and carers; d) feedback and complaints.
4. Continuity of care and relationships – “establishing trusting, empathetic and reliable relationships” (p.13).
5. Enabling patients to actively participate in their care – four responsibilities are highlighted: a) communication; b) information; c) shared decision-making; and d) education programmes (health improvement and self-management of conditions).

Various targets and policies have been introduced to ensure that, not only does the patient voice get heard, but Trusts are accountable for patient experience results. Three major

programmes can be cited here: Patient Reported Outcome Measures (PROMs), the National Surveys Programme, and the Friends & Family Test (FFT). PROMs are patient self-reported clinical outcomes relating to their recovery from operations, such as hip replacements (NHS Digital, 2017). This ensures that the patient's own reported recovery is measured in equal value to clinician's conclusions. The National Surveys Programme has grown in recent years and now covers Inpatient Services, Accident & Emergency Services, Maternity Services, Mental Health Services, Children's Inpatient Services, Cancer Services, and General Practice. Surveys are generally conducted on an annual or bi-annual basis either by NHS Trusts themselves, or by approved third parties. In 2009, improvement against Inpatient Survey scores became a financially incentivised target through CQUIN (DoH, 2008) for all acute hospital trusts.

In 2013, the Friends & Family Test (FFT) (NHS Commissioning Board, 2012) was introduced to the NHS as a measure of patient satisfaction. The FFT asks a simple question to patients: "how likely is it that you would recommend [this service] to a friend or family member should they require similar treatment or care?" It originates from the Net Promoter Score, which is used as a measure of customer loyalty in the US (Reicheld, 2003, 2006; as cited in Picker Institute, 2014). In the East Midlands region in 2012, the SHA at the time began trialling the FFT as a regional CQUIN as a more 'real-time' feedback loop (Picker Institute, 2014). It was later taken up as a national CQUIN, replacing the Inpatient Survey CQUIN (NHS Commissioning Board, 2012).

Its application to the healthcare sector has been controversial and research by the Picker Institute (2014) found that interpretations of the concept of recommending a service to a friend or family member were too varied for it to be a robust measure of patient satisfaction. Despite this, DoH introduced it as a mandatory CQUIN in 2013 for all Inpatient Services. By 2014, all NHS providers – acute hospitals, mental health and community health providers, specialist services, dentists, GP practices and pharmacies – were required to give patients the opportunity to answer the question. This essentially means that every patient in England can now expect to be asked this question. Interestingly, more recently, NHS England has formally recognised the potential inappropriateness of the question in certain circumstances and released guidance in April 2016 that explicitly told providers to "routinely exclude cases that are likely to cause upset or distress", such as in cases of 'bad news' like a terminal illness diagnosis (NHS England, 2016).

1.4.3. Patient involvement in education and research

The involvement of patients in the education of health professionals has also been growing in popularity (Basset et al., 2006; Bury, 2010; Collier & Stickley, 2010; Costello & Horne, 2001; Felton & Stickley, 2004; Forrest et al., 2000; Fox, 2011; Jha et al., 2009; Masters et al., 2002; Morrow et al., 2010; Repper & Breeze, 2007; Rhodes et al., 2014; Schneebeli et al., 2010; Spencer et al., 2000; Towle et al., 2010). The rationale for this is that by involving patients in education, health professionals are more likely to see the patient as an individual, and it encourages a more patient-centred approach to healthcare (Bury, 2010; Costello & Horne, 2001; Jha et al., 2009; Spencer et al., 2000; Repper & Breeze, 2007). It is further theorised that a greater emphasis on the ‘human’ element will encourage trainee medics and nurses to see beyond symptoms and diagnoses to the person (Costello & Horne, 2001; Forrest et al., 2000). As some have criticised the traditional medical model for not being patient-centred and objectifying patients by their illness (Borg et al., 2009; Spencer et al., 2000), involving patients in education seems a logical way to encourage a culture change.

PPI has been utilised in several ways in education: incorporating their views into curriculum development, producing learning materials, and classroom teaching (Jha et al., 2009; Repper & Breeze, 2007). However, as with other PPI methods, many practical and ethical issues have been found (Bury, 2010; Costello & Horne, 2001; Jha et al., 2009; Spencer et al., 2000). There have been concerns that patients’ rights are likely to be neglected, since recruiting patients for education does not go through the same standardised and rigorous process as recruitment for research does (Costello & Horne, 2001; Felton & Stickley, 2004). There have also been concerns that the emotional impact on patients is not appreciated (Jha et al., 2009). Going further than this, Felton & Stickley (2004) found that some teachers suggested that involving patients in a classroom-setting was of much less value than placements, where students experience human interactions in the real-life setting. On the contrary, some have found that PPI in education is beneficial to students, particularly in classroom settings (Costello & Horne, 2001; Schneebeli et al., 2010), and that it encourages students to have more positive attitudes towards patients (Simpson & House, 2002).

Furthermore, PPI in education can be seen as tokenistic, and some question whether it is really changing culture at all against a backdrop of intensely professionalised institutions (Bury, 2010; Collier & Stickley, 2010). Its effectiveness is also not readily evaluated or understood (Jha et al., 2009; Repper & Breeze, 2007). It has also been suggested that

professional bodies do little to promote PPI in education – they do not instil a culture of partnership between patients and healthcare professionals (Baker, 2007). It seems that the traditional medical model, that focuses on symptoms, medication, and procedures, still dominates in practice. In the example of nursing education, the academisation of professions further reinforces this in newly qualified nurses, where patients report being treated like “text book case studies” (Forrest et al., 2000: p.53) rather than individuals.

PPI in health research (that is the design and conduct of research and not just as subjects) has also been growing in popularity (Andrews et al., 2015; Ashcroft et al., 2016; Bagley et al., 2016; Barber et al., 2011; Boote et al., 2010; Boote et al., 2013; Brett et al., 2012; Buck et al., 2014; Crocker et al., 2016; Daveson et al., 2015; Domecq et al., 2014; Ennis & Wykes, 2013; Frith et al., 2014; Ives et al., 2012; Moule & Davies, 2015; Shippee et al., 2013; Staley, 2015; Staniszewska et al., 2011b; de Wit et al., 2013). Indeed, applications to the NHS Research Ethics Committee (REC) specifically ask researchers how they plan to involve patients (Health Research Authority (HRA) & INVOLVE, 2016). According to INVOLVE and HRA, applications to REC that include plans to involve patients and the public have increased from 29% in 2011 to 40% in 2012 (Tarpey & Bite, 2014). However, 40% of those applications appeared not to understand the PPI question in the application form (Tarpey & Bite, 2014), suggesting that PPI continues to be difficult to define and implement in practice.

Ives et al. (2012) argue there are two main rationales for PPI in research: “PPI as means to an end” – to increase the relevance of research to patients; and “PPI as end in itself” – to make research accountable and transparent, and represent the community (p.182). More specifically, the lay perspective can aid the production of more accessibly phrased consent briefings and information, offer insight to aid a wider scope of interpretation of results, and challenge assumptions and accepted practices of the research field (Brett et al., 2012; Boote et al., 2010; Ives et al., 2012). Ives et al. (2012) claim, however, that there is a paradox in PPI in health research. PPI is valued because of the relatively ‘objective’ outsider view of a layperson, but that by significantly involving them in the design, conduct, analysis and reporting of PPI, the layperson becomes professionalised (as already discussed in section 1.2.2), and as such, there is a risk that PPI becomes ineffective or tokenistic.

1.4.4. Barriers to PPI

It is widely acknowledged in the literature that there are multiple barriers to successful participation, many of which have already been alluded to in the previous sections. They range from technical and practical barriers, to cultural and organisational barriers, to personal attributes and characteristics of those involved. When PPI is reviewed from a pragmatist perspective, these issues are crucial to our understanding of PPI and its (sometimes lacking) impact.

Some of the barriers cited in the literature relate to practical issues, such as a lack of dedicated resources (Attree et al., 2010; Baggott, 2005; Beresford, 2010; Boyce, 2001; Day, 2008; Donaldson et al., 2007; Franklin & Sloper, 2005; Jones et al., 2004; Lightfoot & Sloper, 2003; Matthews, 2001; McEvoy et al., 2008; Parsons et al., 2010; Tait & Lester, 2005; Thomas et al., 2010), logistical problems (Costello & Horne, 2001; Contandriopoulos, 2004), and a complaint that decisions take longer to make (Crawford et al., 2002). Brown (2000) also found that participation activities in general practice were far more likely within larger, well-funded practices, again suggesting that resources are a key ingredient. The logistical barriers, such as being unable to hold meetings in an easily accessible location, can also be very challenging (Beresford, 2010; Matthews, 2001; Rutter et al., 2004; Stevens & Tanner, 2006; Thomas et al., 2010), especially when resources are scarce.

One of the main barriers that service providers and organisations cite is a lack of interest of the public to get involved, or ‘apathy’ (Brown, 2000; Gagliardi et al., 2008; Lehoux et al., 2012; Lowndes et al., 2001a; MacDonald & Taylor-Gooby, 2010; Matthews, 2001; Pickard & Smith, 2001). Sometimes this can be simply a lack of awareness of opportunities to get involved (Brown, 2000; Lowndes et al., 2001b), or sometimes laypeople can hold a negative view of an organisation, and this deters them from getting involved (Kearney, 2004; Lowndes et al., 2001b). Furthermore, others cite the problem of ‘consultation fatigue’ (Beresford, 2010), which is perhaps a symptom of the increasing consumerist approach to healthcare. Anton et al. (2007) also found that professionals report significant difficulties in recruiting participants who can represent the views of those who do not wish to be involved, particularly minority and vulnerable groups.

Some have also discussed the organisational and structural barriers to involvement. The bureaucracy in large organisations can present barriers to PPI (Anderson et al., 2002; Boyce,

2001; Farr, 2012; Hodge, 2005; Matthews, 2001; Rutter et al., 2004). Policies such as Criminal Records Bureau (CRB) checks (Mockford et al., 2016; Renedo & Marston, 2015c) can limit starting PPI work. Franklin & Sloper (2005) identified that there can be many bureaucratic barriers specific to the involvement of children – issues such as safeguarding and health and safety, which often prevented organisations from involving children at all. PPI is also often found to be more prominent in departments and areas of services where the least technical and lowest clinical interventions are needed (Fudge et al., 2008; Franklin & Sloper, 2005) – this may be for organisational reasons or simply practical ones. More generally, Anderson et al. (2002) point out that the NHS is “not designed to be democratic” because of the “inward looking risk-averse bureaucracy” (p.13).

Boyce (2001) found that “bureaucratic rules and regulators” (p.1557), such as policies, restrictions on who to consult, and the lack of organisational structure to support PPI (e.g. dedicated roles), present significant barriers to effective PPI. Furthermore, Baker’s (2007) research on involvement of laypeople in a professional body found that the existing structures for governance and strategic developments did not allow for adequate lay representation, or for their views to have any significant bearing on decisions. Haigh (2008) argues that institutional powers like these need to be challenged for participation to be effective. Furthermore, Carr (2007) argues that, because organisational structures and procedures do not appear to be well set up for effective PPI, it becomes a tokenistic legitimisation function, allowing professionals to maintain power over decision-making.

Some of the barriers for patients and laypeople have already been mentioned, from a simple lack of interest or awareness, to fear of organisations, to practical barriers. Another barrier is the lack of confidence or ability of people to get involved (Day, 2008; Felton & Stickley, 2004; Franklin & Sloper, 2005). In addition to these issues, it has also been found that individuals are less likely to get involved if they do not feel their involvement will have impact and are suspicious of professionals’ commitments to involving them (Beresford, 2010; Carr, 2007).

1.4.5. A complex combination of barriers

The previous section has highlighted the varying barriers experienced by various stakeholders in PPI processes, which suggests they are multifaceted and may differ from one context to another. It is likely that a combination of barriers is at play. Anton et al. (2007)

identified three 'tensions' in the implementation of Government PPI policy through interviews with key stakeholders. These were: 1) informing versus consulting (some view informing the public as enough whilst others value active involvement in consultations; 2) the legitimacy of representative versus direct voices (some view representatives as sufficient involvement whereas others value direct involvement from individuals); and 3) prescriptive versus flexible assessment processes (Government agency-prescribed methods offer consistency nationally, but do not allow for localised adaptations).

A study by Basset et al. (2006) focusing on the barriers of involvement in mental health education (but which can also arguably be applied to other areas) identified 10 barriers: 1) hierarchies that exclude (referring to the professional hierarchies of universities); 2) stigma and discrimination (of having a mental health condition); 3) validation and accreditation processes (to validate recruitment); 4) academic jargon and 'put-downs' (complicated language that distances the patient); 5) clever people/clever excuses (such as the unrepresentative argument); 6) knowledge as king and topics/levels (the focus on expert knowledge); 7) individual rather than team approach (culture of higher education tends to be about individual gains); 8) gaining access (recruiting patients can be difficult); 9) bureaucratic payment systems (delays of which can be particularly problematic for mental health service users); and 10) lack of support for trainers/educators (such as a lack of adequate preparation for sessions).

Focusing on service user involvement in social care, Carr (2007) identified three main causes of a lack of impact, which can also apply to other fields including healthcare: 1) Professionals being challenged by service users causes conflict and the professionals inevitably ignore feedback. 2) Some suggestions for changes are ignored simply because they are related to wider issues which cannot be rectified. 3) Organisational resistance to devolved power to the people out of fear. The barriers described in the previous sections, and the issues found in these three studies from Anton et al. (2007), Basset et al. (2006), and Carr (2007), demonstrate that many barriers appear to be systemic and cultural, and therefore, not easily overcome. The following section describes the facilitating factors found in the literature, as well as some of the strategies that have been shown to be successful in overcoming the barriers.

1.4.6. Facilitating factors

Though there have been numerous barriers reported in the literature, some have also reported facilitating factors. Good relationships between service users, groups and service providers has been highlighted as an important facilitating factor (Anderson et al., 2006; Attree et al., 2010; Bovaird, 2007; Enehaug, 2000; Lopes et al., 2015; McEvoy et al., 2008; Parsons et al., 2010). To quote Bovaird (2007), who discussed user involvement in the co-production of public services, “co-production means that service users and professionals must develop mutual relationships in which both parties take risks” (p.856). Given that PPI is essentially about working together towards a (presumably) shared goal, forming and maintaining good relationships is logically inherent to this process.

Others have cited communication as essential to the PPI process (Barnes et al., 2004; Barnes et al., 2006; Cavet & Sloper, 2004; Forsythe et al., 2015; Parsons et al., 2010). Again, this is unsurprising given that PPI is often a deliberative process, involving debates on various (sometimes emotive) topics. Conversing in terms that are understandable to all stakeholders is key to effective communication in these scenarios – Hitchen et al. (2011) reported that service users find jargon and technical language challenging to interpret and respond to. More specifically, some have cited the value of ‘story telling’ style interactions (Barnes, 2005; Borg et al., 2009; MacDonald & Taylor-Gooby, 2010). Young (2000), as cited in Barnes (2005), describes how three forms of communication should be valued over and above formal, professional, and rational forms of talk: ‘greeting’ (every-day acknowledgement of one another), ‘imagery and playful language’ (passionate and emotional description), and ‘narrative’ (story-telling to express feelings and experiences).

Some research has also suggested that participation works better when it is at a ‘grass roots’ level. Formal structures and activities appear to stifle active participation due to the tedious nature (Attree et al., 2010; Barnes et al., 2004; Barnes, 2005; McEvoy et al., 2008), making it more likely to be tokenistic, and this can make it unattractive to participants (Anderson et al., 2006). As Barnes et al. (2004) point out, the mere setting up of opportunities does not necessarily mean that a fair discussion and active involvement will happen. In addition, in the context of research, it has also been suggested that the earlier PPI happens in the process, the greater the outcomes (Daveson et al., 2015; Dudley et al., 2015; Snow et al., 2015; Supple et al., 2015), though there is evidence that few research studies involve patients

and the public at early stages (Gamble et al., 2014). According to Jinks et al. (2016), PPI also needs to be well embedded over a long period to make it effective and sustainable.

Bovaird (2007) also interestingly suggested that the contextual and historical antecedents partly determine the outcome of PPI. The historical context can potentially be equally facilitative and detrimental to successful participation. Anderson et al. (2002) noted that many methods of PPI in PCGs were at least partly influenced by prior relationships. As referred to at the beginning of this section, a major facilitating factor is that of good quality relationships. Relationships often have a historical context, as relationships must build over time. As such, the historical antecedents (such as a historical poor reputation) can also have an influence on PPI. This is summed up in a quote from Bovaird (2007: p.848):

“Co-production will evolve along path-dependent lines from different antecedents and will be shaped by different motivations on behalf of both professionalised service providers and the users and communities involved.”

More generally, factors such as willingness, commitment and cooperation between stakeholders have been cited as important in PPI (Anderson et al., 2002; Costello & Horne, 2001; Wilson et al., 2015). Leadership, trust, good relationships, confidence, and knowledge of individual stakeholders (Anderson et al., 2002; Anton et al., 2007; Kearney et al., 2017; McEvoy et al., 2008; Parsons et al., 2010; Wilson et al., 2015) have also been cited as facilitating PPI. Service users have cited a range of factors they believe facilitate successful PPI, many of which focus on treating them as partners, and building their skills and knowledge to contribute effectively (Renedo & Marston, 2015b). Beresford (2010), for example, reported several factors service users believed were important. These included being listened to and valued, meeting access requirements, providing adequate support and training, and building trust amongst all stakeholders.

In the case of involvement in research, the ‘FIRST’ model has been developed by Hewlett et al. (2006) to aid researchers in successfully involving patients as partners in research. It contains five factors to facilitate involvement: 1) Facilitate: inclusion and contribution; 2) Identify: projects and potential partners; 3) Respect: roles and contribution; 4) Support: confidentiality and communication; and 5) Train: research processes (p.678). The

model suggests researchers consider various questions as a checklist for facilitating successful involvement.

To 'Facilitate', they suggest considering various practical aspects: utilising accessible venues and times, identifying specific tasks patients can be involved in, and providing practical support such as reimbursing expenses. For 'Identify', they suggest writing a job description, and checking the patient is willing and confident in certain tasks. For 'Respect', they suggest it is necessary to understand the patients' personal skills, how to develop their skills, and practical issues such as signing contracts. To aid 'Support', they suggest the patient should read and understand the research protocol, have one-to-one meetings with the principle investigator, and ensure the patient has accessible contact details. Finally, with regards 'Train', they suggest formal training should be given where the need for it is identified and desired by the patient.

Many of these factors have been found to be important in other areas that involve patients, so a simple model like this could be applicable to various contexts. However, when de Wit et al. (2015) applied this model in practice, they found it to be limited and suggested it needed expanding. Specifically, they suggest it needs to include more specific advice regarding the role of the principal investigator. They identify their role to be pivotal in facilitating the successful involvement of patients in the whole research process. The difficulty defining roles of individuals has already been described in section 1.3.3. and will be returned to in section 1.6.3. when discussing models and conceptualisations of PPI.

Another study suggested that the values placed on PPI by researchers can also influence the impact of PPI (Gradinger et al., 2013). They identified three value systems: 1) ethical or political issues (including empowerment, accountability and ethics) (normative values); 2) consequences of PPI in research (including effectiveness, quality, and validity) (substantive values); and 3) conduct of PPI (including partnership, respect and openness) (process values). Gradinger et al. (2013) argued that these values need to be explicitly set out by researchers whom are considering PPI in their work from the beginning in order to more successfully manage conflicts that may occur when values are opposing.

1.4.7. Summary

What is clear from the literature is that there is no one way that organisations involve patients and the public, and that a multitude of methods are utilised for a range of purposes and reasons. A one-size-fits-all approach does not appear to work (Anderson et al., 2006; Barnes et al., 2007; Cavet & Sloper, 2004; Gott et al., 2002; Lightfoot & Sloper, 2003; Morrow et al., 2010; Tambuyzer et al., 2011), and methods often need to be tailored to the target audience (Gott et al., 2002; Lowndes et al., 2001a). Indeed, Gott et al. (2002) specifically recommend organisations set up formal mechanisms of PPI as well as outreach programmes. There are also a multitude of barriers and facilitating factors, as already discussed in sections 1.4.4-6. Furthermore, evidence suggests that professionals are often not clear what the purpose of participation is in general, nor are they clear what the role of laypeople is in the decision-making process (Baker, 2007; Callaghan & Wistow, 2006; Enwistle & Watt, 2006; Forbat et al., 2009; Gagliardi et al., 2008; Ocloo & Matthews, 2016). Given the range of methods employed, and the potential lack of robustness, along with the multiple barriers and facilitating factors, it is reasonable to deduce that it may be difficult to measure the impact and effectiveness of PPI. As such, what follows in the next few sections is a discussion of the impact (or lack of) of PPI and how some have attempted to measure success.

1.5. The elusive impact of PPI

There is a wide range of research that has found PPI often does not seem to have an obvious impact or significant outcomes (Bovenkamp & Zuiderent-Jarek, 2013; Callaghan & Wistow, 2006; Cavet & Sloper, 2004; Evans et al., 2013; Fudge et al., 2008; Hudson, 2015), and it appears there is limited influence on policies or strategic direction (Attree et al., 2010; Jha et al., 2009; Richardson et al., 2005; Rutter et al., 2004). Indeed, even participants themselves are sometimes unable to identify the benefits of PPI (Cotterell et al., 2010; Lightfoot & Sloper, 2003). There is also evidence that PPI does not lead to shared powers over decision-making (Pickard & Smith, 2001; Rutter et al., 2004).

1.5.1. *A lack of reporting of impact*

It is worth noting, however, that many research papers either do not necessarily set out to assess impact and effectiveness, or are not able to assess impact and outcomes in the timeframes and parameters of their research. Many studies of PPI have been qualitative case studies of individual processes or activities (e.g. forums and panels) to observe the relationships and interactions between professionals, and patients and laypeople; and understand individual perspectives on PPI. Therefore, assessing impact and outcomes was not the primary focus.

The lack of measurement of impact in research papers, (or at least the lack of reporting of impact), has been particularly noted in three systematic reviews: one in 2002 by Crawford et al., one in 2012 by Mockford et al., and another in 2012 by Conklin et al. Beginning with Crawford et al. (2002), it was identified that, of 337 papers on PPI between 1966 and 2000, 294 (87%) did not report any findings on the effectiveness or impact of PPI. Furthermore, they found no studies that assessed the wider possible impact of PPI on satisfaction with health services, quality of life, or health outcomes and wellbeing. Most of the 42 papers that reported on the effectiveness and impact of PPI were case studies of individual activities and processes that resulted in small changes to services (e.g. changes to patient information, or simplifying appointment systems).

Mockford et al. (2012) reviewed PPI in healthcare studies in the UK between 1997 and 2009 (studies of involvement in own care, children's services, research and education, and the voluntary sector). Of 64 eligible papers, 42 were included (which represented 28 studies);

again, showing that many studies report no impact at all. The majority of studies reported no clear definition of PPI, making it difficult to understand what was being measured, and, therefore, making it even more difficult to measure impact. Only 2 studies reported an explicit theoretical perspective upon which their study was based. The systematic review concluded that the lack of impact of PPI is unlikely to be indicative of an actual lack of impact, but possibly simply a lack of reporting of impact.

Conklin et al. (2012) reviewed research papers of public involvement in healthcare policy between 2000 and 2010. Of 137 identified papers, 19 were included in their review, again, showing that most papers do not state any measurement of impact and effectiveness. Of the 19 papers, most were unclear what effects were being measured. Most appeared to measure effectiveness based on the perceived impact the public felt they had on decision making. Conklin et al. (2012) also noted that most papers did not explicitly reference how ‘the public’ was defined, making it difficult to understand the approaches and types of public involvement being examined. Studies that reported impact either found there were small changes to policies, or limited or mixed impact on policy development. Finally, Conklin et al. (2012) also found that many authors reported a ‘positive impact’ but merely described an effective deliberation process, suggesting that some view good public involvement to be valuable in itself, and not necessarily requiring tangible outcomes.

All three systematic reviews have one major finding in common – all have found there is a lack of clarity and consistency in how successful PPI is defined and how impact is measured. This means that, when studies do cite successful outcomes and a positive impact of PPI, it is difficult to challenge them. Furthermore, Anton et al. (2007) pointed out that the discussions in the literature about how one might measure impact and effectiveness also lack a consensus.

1.5.2. Positive outcomes and impact

There are, however, some studies that do highlight positive outcomes of PPI. In Crawford et al.’s (2002) systematic review, 8 studies found PPI seemed to increase positive attitudes of staff to further involve patients and the public, which was deemed to be potentially evident of organisational culture change. Similarly, in Mockford et al.’s (2012) systematic review, 15 studies reported new and improved services; 11 reported improved information and dissemination; and 9 reported changes in staff attitudes towards PPI. This

finding was also noted by Lightfoot & Sloper (2003) (though it is important to note their study only involved interviewing 3 staff members). As an illustration of the change in attitude, one nurse in Lightfoot & Sloper's (2003) study said:

"It really did change my whole outlook on nursing...I became from that point on the person who was always saying 'well, why are we doing this? Why do we need to do it like that? Have we asked patients what they want?'" (p.283)

There are also several studies that show how PPI can improve the confidence, self-esteem, knowledge, and skills of the patients and laypeople that participate (Anderson et al., 2006; Ashcroft et al., 2016; Burton, 2009; Costello & Horne, 2001; Evans et al., 2013; Fudge et al., 2008; Jha et al., 2009; Lightfoot & Sloper, 2003; Masters et al., 2002; Matthews, 2001; Mockford et al., 2016; Spencer et al., 2000; Stevens & Tanner, 2006; Tierney et al., 2014). The achievement of these improvements is sometimes even the individual's motivation for getting involved (Freitas, 2015; Thompson et al., 2014). Furthermore, Cotterell et al. (2010) found that cancer patients being involved in service developments also improved their ability to cope and live with their condition, and extended their support network. In addition, in Tait & Lester's (2005) review of service user involvement in mental health care, involvement was identified as having therapeutic benefits to service users. Rhodes et al. (2014) also found patients' health and wellbeing can even be improved by taking part in the education of health professionals.

In the case of PPI in research, systematic reviews by Brett et al. (2012) and Tierney et al. (2014) show PPI can lead to more patient-focused research objectives, the development of clearer and more user-friendly information, questionnaires and interview schedules, and more appropriate recruitment methods, as well as increasing the focus of data analysis on outcomes for patients. Ennis & Wykes (2013) also interestingly found a statistically significant association between PPI in research and achievement of subject recruitment targets, and other studies claim it can make funding applications more successful (Andrews et al., 2015; Boote et al., 2013). A study by de Wit et al (2015) found that involving patients increased the validity of a patient-reported outcome measure, and Rose (2014) reports that patients can ensure research findings are more patient outcome-focused. Domecq et al.'s (2014) systematic review also found that PPI increased recruitment rates, and researchers were more successful with funding bids and defining relevant outcomes for research. Similar benefits

were also reported by Mockford et al. (2016) and South et al. (2016) – securing funding, highly successful recruitment, and increased skills and confidence. In addition, Gillard et al. (2012) and Garfield et al. (2015) reflected on their experiences of involving laypeople in the analysis and collection of data and claimed that laypeople challenged their academic assumptions, producing different knowledge contributions.

1.5.3. Are there negative outcomes or costs?

Having highlighted the positive outcomes and impact of PPI, it is pertinent to explore if there are any negative outcomes or costs. Staniszevska (2009) points out the lack of specific research on the negative impact of PPI, but a small number of studies do report costs and negative outcomes. Brett et al.'s (2012) systematic review of the impact of PPI on research found that some studies have reported 'challenges' to the research process. Involving patients in the research design and planning process sometimes led to the proposal of less scientifically robust methods, and raised some ethical reconsiderations. For example, in two clinical trial studies, patients were reportedly concerned about the ethics of deceiving patients about whether they were on treatment or not in a randomised controlled trial, and as such, the design of the study changed to include a non-placebo group. This compromise met the ethical concerns of the patients, but potentially reduced the robustness of the study. In addition, they also found some studies that reported increased costs and that processes sometimes took longer – something also described by Fairbrother et al. (2016) when reflecting on involving patients in their research.

Mockford et al.'s (2012) systematic review noted a lack of reporting of economic costs of PPI. Pizzo et al. (2014) note the same – their literature review showed that, whilst there are reports of five groups of benefits (effects on NHS governance and legitimacy; effects on research design and implementation; effects on efficiency in the design and quality of projects; effects on participants and citizenship (the so called 'feel good' effect); and effects on equity issues); there was little reference to the economic costs. They suggest that this is because costs are often not measured at the time, and it is then difficult to measure retrospectively.

Furthermore, Jones et al. (2004) suggested that, if PPI is to be increased in the setting of general practice, then GPs would need training on ways of "addressing rationing dilemmas" (p.101). By this they were referring to the conflicting role GPs have in being advocates for

patients whilst simultaneously considering wider issues such as budgets for the whole community. Pizzo et al. (2014) also cite there appears to be a reluctance to cost PPI in economic and monetary terms, as this is perceived as too reductionist. This potentially points to a pre-occupation in the field with the assumption that PPI is an inherently good thing and that the costs are irrelevant or unimportant; something that Contandriopoulos (2004) also argued.

An example of a study that specifically explored the costs of PPI was a randomised controlled trial (of which there are very few) of PPI in setting healthcare priorities in Canada (Boivin et al. 2014). The group that involved patients cost 17% more and took 10% longer to make decisions. The study did, however, find that involving patients resulted in a greater emphasis of priorities on access to services, empathy of health professionals, supporting self-care, and patient involvement in clinical decision-making. In the group that did not involve patients, priorities were focused more on the technical side of treatment and symptom management. As such, when developing PPI activities, stakeholders potentially need to decide if the benefits outweigh the costs.

In addition to a lack of reporting about the costs of PPI, there is also a lack of consideration in existing research of the possible negative impact and outcomes on participants. One such study that identified negative effects on participants was by Hitchen et al. (2011), which found that there was a considerable emotional impact on mental health service users. As already described, there are many potential personal benefits of getting involved (improved self-esteem for example), but the considerable emotional impact from sharing personal experiences is often not appreciated by professionals (Hitchen et al., 2011; Jha et al., 2009).

1.5.4. Can we measure impact and outcomes?

Overall there appears to be a lack of clear and consistent measurement of impact, outcomes, and effectiveness of PPI. This has been increasingly raised as an important issue to address in the field (Conklin et al., 2012; Mockford et al., 2012; Purtell et al., 2012; Shippee et al., 2013; Staniszewska 2008, 2009). In addition, as PPI in research and education has been growing, there have been calls for more robust and effective ways of measuring the impact in these areas specifically (Barber et al., 2011; Brett et al., 2012; Crocker et al., 2016; Ennis &

Wykes, 2013; Esmail et al., 2015; Morrow et al., 2010; Staley, 2015; Staniszewska et al., 2011a, 2011b).

Hudson (2015) has developed a set of criteria by which PPI (or patient and public engagement (PPE) as his article refers to it) could be assessed, as shown in Table 4. The criteria include suggestions such as reduced demand for emergency services and improved health outcomes – criteria that Crawford et al. (2002) found no articles reported. This proposed set of criteria could provide the building blocks for the measurement of impact and effectiveness of PPI in the future. Furthermore, Rowe & Frewer (2000) suggest two key types of criteria for evaluating participation: acceptance criteria, which comprise representativeness, independence, early involvement, influence, and transparency; and process criteria, which comprise resource accessibility, task definition, structured decision-making, and cost-effectiveness.

Table 4: Assessing PPE effectiveness (Hudson, 2015: p.14)

Instrumental	Intrinsic
More responsive services leading to greater patient satisfaction	Building networks of support and strengthening mutual connections
Creation of new or improved services	Feelings of closer connection to the political realm
High utilisation of new services	Strengthened geographical communities and communities of interest
Improved health outcomes with patients better able to manage their condition	Reduction in social exclusion
Reduced demand for emergency services	Increased access to decision-makers
Reduced need for primary and secondary care	Increasing numbers of people participating in decision-making

In the case of specifically assessing mechanisms in the NHS, Harrison et al. (2002) propose a set of questions that should be asked within three groups: intentions, involvement processes, and outcomes (see Table 5.). They argue that the main question evaluators of PPI should be attempting to assess is the “extent to which management decisions have been influenced or modified as a result of involvement” (p,66). One of the key points they also make is that methods and outcomes should be in line with the original aims of the activity.

Similarly, Abelson et al. (2015) identified four principles of good quality engagement through a collaboration with various international PPI researchers as a tool to aid organisations to assess their engagement activities. Table 6 summarises the core principles and measures. In the specific context of PPI in research, Edelman & Barron (2015) argue that we cannot truly measure impact whilst PPI in research is viewed as an intervention rather than a routine part of the process. This may have implications for PPI in other contexts.

Table 5: Issues in evaluating NHS involvement mechanisms (Harrison et al., 2002: p.65)

	Questions
Intentions of the NHS body	<ol style="list-style-type: none"> 1. Is the aim to involve the general public in the territory covered by the NHS body? Or patients/users of the organisation? Services provided or commissioned by the organisation? 2. Is the aim one- or two-way? Specifically: <ul style="list-style-type: none"> • To give information to public/users? • To legitimate management decisions in terms of public/user opinion? • To seek information and/or opinion from public/users? • To engage in a dialogue with public/users? • To encourage public/users to be more active in the field?
Involvement processes	<ol style="list-style-type: none"> 1. Are the processes adopted consistent with the ostensible aim? 2. How wide and inclusive are the involvement processes, and who determines who is involved? 3. Which parties determine the agenda in respect of which involvement is to take place? 4. How does the organisation respond to proactive approaches from external groups?
Outcomes	<ol style="list-style-type: none"> 1. Can the organisation give convincing accounts of decisions that have been different as a result of involvement? What would have happened otherwise? 2. By what, if any means, has the organisation explained and accounted for its decisions to public and users?

Table 6: Principles of quality public and patient engagement and organising frameworks for evaluation tool (Abelson et al., p.822)

Guiding principles for quality public and patient engagement (PPE)	Organising framework
The principles of inclusivity, diversity, capacity and accessibility guide the selection, support and involvement of participants in all PPE activities	Integrity of design and process Assessing the integrity of the PPE design and implementation is central to ensuring the process adheres to the features of high-quality PPE
The principles of integrity, accountability, and transparency guide the design and implementation of all PPE activities	The principles of integrity, accountability, and transparency guide the recruitment, selection, support and involvement of participants in all PPE activities
PPE activities are undertaken to influence and exert impacts on participants, organisations and decision making	Influence and impact The output obtained from high-quality PPE activities is linked to relevant decision-making processes within the organisation
PPE activities are supported by a participatory culture	Participatory culture High quality PPE is supported by a culture of participation within the organisation
PPE activities seek to promote the principles of collaboration, shared purpose and improve governance	Collaboration and common purpose High quality PPE supports and encourages internal and external stakeholders to work together to advance common goals

Finally, in addition to defining and assessing impact, Staley (2015) also argues we should unpick when and how different impacts and outcomes are achieved, taking into consideration contexts and differing methods of PPI. Bovaird (2007) demonstrated how PPI can be successful in a range of contexts and for a range of purposes (e.g. co-delivery of services) in a review of various case studies – what they had in common was a clear definition from the outset about the purpose and roles individuals would take. Furthermore, there has been a suggestion that we may benefit from involving patients and the public in defining measurements of successful PPI (Staniszewska et al., 2011a), though this would not necessarily lead to any more consensus than there is amongst academics. Anton et al. (2007) found, for example, that the only criteria their participants (both professionals and laypeople)

could agree was that “people want to see they have been listened to” (p.479) for PPI to be ‘good’; and quite how this could be measured is open to debate.

1.5.5. Summary

The previous sections have demonstrated how complex and multifaceted PPI is, and that there is difficulty in defining and measuring its impact. So, the question remains ‘is it worth doing?’ The short answer might be ‘it depends’, as Staley (2015) concludes. Can the benefits and positive outcomes (which are difficult to measure) outweigh the costs (which are also unclearly defined)? And to whom do these benefits and costs relate? (Staniszewska et al., 2011a) Or should it simply continue because it is deemed to be a morally good thing to do? Contandriopolous (2004) points out that organisations need to decide if they want more participation because of its democratic principles, or if they want greater satisfaction with services (rendering PPI potentially unnecessary). As such, there needs to be clearer conceptualisation and theory about what PPI is, how it works, and what the roles of individuals involved are, with explicit consideration of the context. The following sections examine existing conceptualisations, models, and theories of PPI, before presenting the case for a different approach in conceptualising PPI – the main aim of the PhD study.

1.6. Conceptualisations of PPI: A continuum, a process, or something else?

Several authors in the field have developed models and theories of PPI. They have theorised about participation at the individual level (e.g. patient involvement in their own care), and at a group level (e.g. activist groups). Theories vary in terms of their interpretations and in the evidence drawn upon (if any). Dachler & Wilpert (1978) argued that theories fall into one of four categories: democracy theory, socialist theory, human growth and development theory, and productivity and efficiency theory. They also argued that, depending on the theoretical and ideological standpoint of the author, the interpretation of the nature and purpose of PPI will vary. Furthermore, Dachler & Wilpert make a criticism of the literature for being pre-occupied with an ideology that assumes participation is an inherently ‘good’ thing not to be challenged, leading to a lack of empirical investigation. The following sections describe these theories and models, discussing their strengths and weaknesses. They have been split into four categories: process models, hierarchical models, models focusing on role definitions, and models on the wider aspects of PPI. The term ‘model’ will be used from hereon in for consistency, as this appeared to be the most commonly used term in the literature.

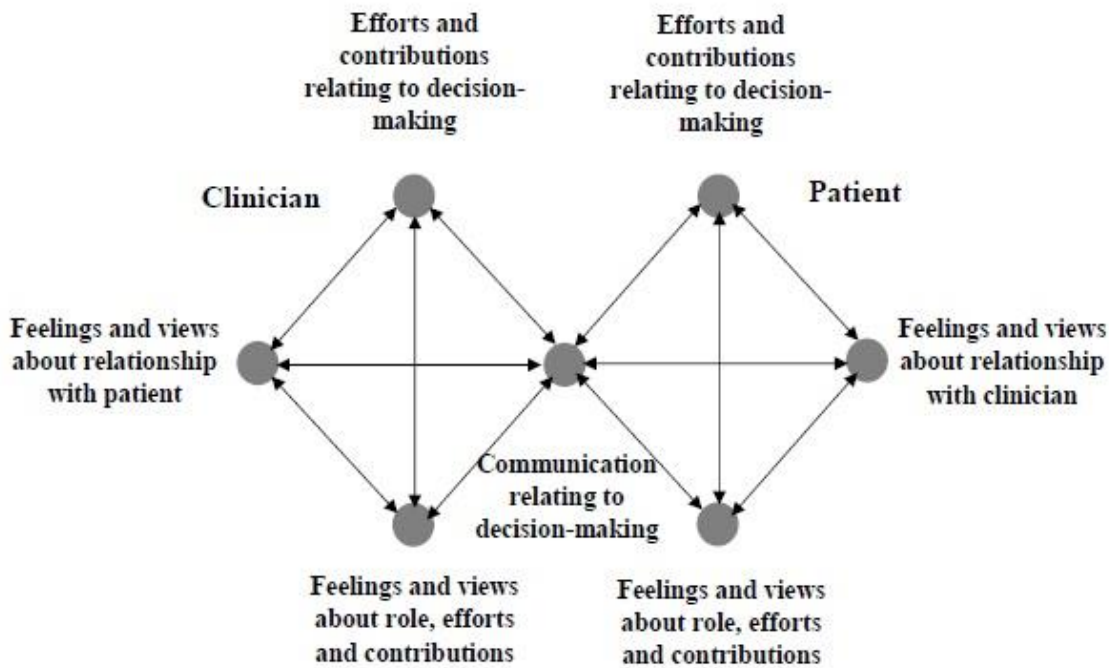
1.6.1. Process models

Some models focus on specific processes, such as the process of patient-doctor decision-making in individual consultations. These models focus on the key factors involved in that process, the patient-practitioner interactions, and the desired outcomes. These models make a more psychological interpretation than others – they focus on the individual, their beliefs and motivations, and how they interact with professionals. Factors such as personality, attitudes and self-confidence are key considerations. They are also very focused on the patient, rather than a layperson or consumer. The language used, therefore, has rather paternalistic connotations, which is somewhat different to other models that appear to be more consumerist in their interpretations.

Enwistle & Watt (2006) developed a framework (Figure 6) that highlights how factors such as beliefs about relationships, beliefs about roles, and efforts made by individuals to contribute to decision-making are key to understanding such interactions. This conceptual framework was developed following a review of other models specific to patient-practitioner communication. Enwistle & Watt (2006) argued that previous models had only focused on

aspects of communication, and not on individual factors such as beliefs. What is lacking from Enwistle & Watt’s framework is the outcome – they have not attempted to convey what factors contribute to effective patient-practitioner decision-making, nor have they defined what effective joint decision-making is. Furthermore, as we will see from other models, they have not made explicit reference to circumstances and context.

Figure 6. *Aspects of patient involvement* (Enwistle & Watt, 2006, p.273)



Thompson (2007) has made these considerations. Thompson developed a taxonomy for patient-practitioner consultations that considers the context and circumstances within which the consultation is taking place. Thompson (2007) took a more deterministic view by suggesting that there are various levels of involvement, which are determined, or at least influenced, by the circumstances in which the consultation is occurring. Factors such as the nature of the patient’s condition (acute vs. chronic), as well as individual factors such as personality and relationship with the practitioner, are key to determining the level of involvement. If, for example, the patient’s condition is very serious and acute, they will be less involved in decision-making due to the urgent nature of the required decisions.

Thompson (2007) also did not make the assumption that greater levels of involvement in decision-making should be aspired to, but instead argued that the level of involvement

should be determined by the circumstances, and also the patient’s wishes. In other words, practitioners should involve patients but only where it is appropriate and practical to do so, and upon the patient’s wishes. This taxonomy was also developed from empirical data, rather than a review of others’ works like Entwistle & Watt (2006)’s, where their access to empirical data would have been limited. Thompson developed the taxonomy over numerous iterations from a series of interviews and focus groups. As such, this framework encompasses a comprehensive representation of the factors involved in the process of consultation.

In an earlier model by Charles et al. (1999), the focus is again on the process of interaction between patient and practitioner, but instead acknowledges that the type of exchange and decision-making process may evolve as the interaction evolves. As shown in Table 7, they highlighted three stages of interaction: information exchange, deliberation, and treatment decision. However, unlike Entwistle & Watt (2006) and Thompson (2007), Charles et al. (1999) have not incorporated individual factors, such as individual preferences for the type of exchange. As such, a combination of the models discussed so far may have more value for examining patient-practitioner interactions in the decision-making process. These theories also touch on factors that may be important when examining wider participation, such as the co-design and delivery of services.

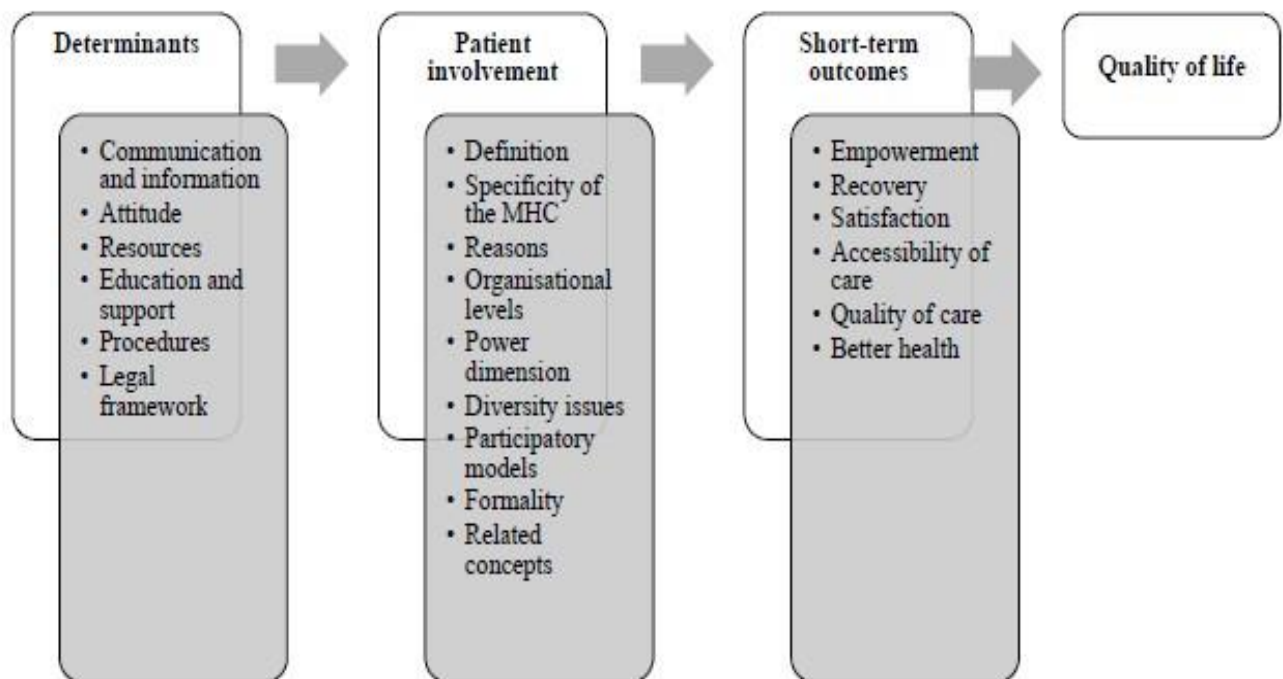
Table 7: Models of treatment decision-making (Charles et al. 1999: p.653)

		Models		
Analytical stages		Paternalistic	Shared	Informed
<i>Information exchange</i>	Flow Direction Type Amount	One way (largely) Physician → patient Medical Minimum legally required	Two way Physician ↔ patient Medical and personal All relevant for decision-making	One way (largely) Physician → patient Medical All relevant for decision-making
<i>Deliberation</i>		Physician alone or with other physicians	Physician and patient (plus potential others)	Patient (plus potential others)
<i>Deciding on treatment to implement</i>		Physicians	Physician and patient	Patient

Another model by Tambuyzer et al. (2011) (Figure 7) describes the process of patient involvement in mental health care based on a systematic review of the literature. The model describes ‘determinants’ of patient involvement (communication and information, attitude, resources, education and support, procedures, and legal framework); characteristics of the involvement (definition, specificity of mental health care (e.g. inpatient), reasons for involvement, organisational levels, power dimensions, diversity issues, methods, formality, and related concepts); short-term outcomes (for the patient) (empowerment, recovery, satisfaction, accessibility of care, quality of care, better health); and the long-term outcome quality of life.

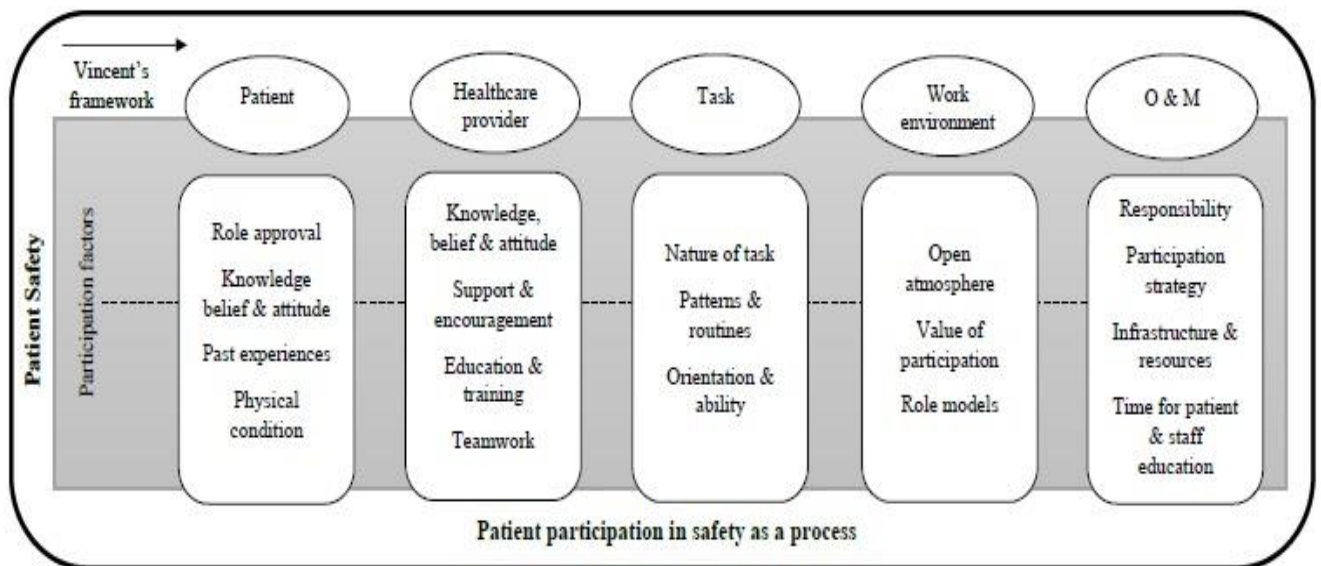
The model is presented in a deterministic manner – the factors determine the characteristics of the involvement, which in turn determines the outcomes, both short-term and long-term. This model has acknowledged that the potential for issues such as resources and procedures at the organisational level to influence patient involvement is present, and has gone so far as to suggest they *determine* patient involvement. This model differs from the previous models discussed in that it has examined factors that occur outside of the process of PPI. However, it has been criticised for not taking enough consideration of culture (Tse et al., 2012).

Figure 7: Model of involvement (Tambuyzer et al., 2011: p.141)



The final model discussed in this section is by Vaismoradi et al. (2015) and is based on Vincent et al.'s (1998; as cited in Vaismoradi et al., 2015) framework of patient involvement in patient safety. The model was further developed by Vaismoradi et al. (2015) following application of the model to a systematic review of the literature on patient involvement in patient safety. Where this model differs to the models already discussed is it makes much more explicit references to contextual factors – the work environment, characteristics of the activity, and the organisation and management (Figure 8). As such, this model acknowledges the influence contextual factors can have on the roles of individuals in the process of PPI. However, this model is still potentially over-simplified, as it does not consider any external influences, such as Government directives.

Figure 8. Schematic of patient participation in patient safety (Vaismoradi et al., 2015, p.632) (O&M = Organisation & Management)



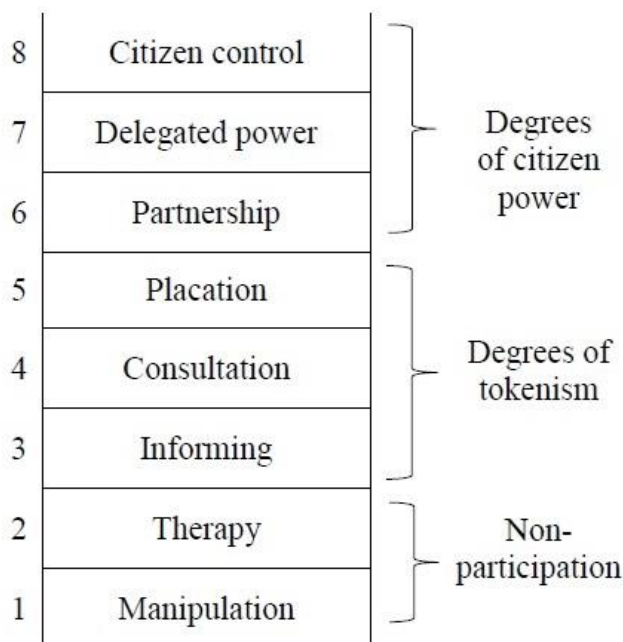
The models already discussed attempt to examine and explain involvement at the micro process level, where the primary focus is on the individuals involved. Although there is some reference to context and environmental factors, the primary focus is on motivations and characteristics of the individuals (with the exception of Vaismoradi et al., 2015). Reflecting back on Dachler and Wilpert's (1978) interpretation that models of PPI can be categorised into one of four categories, those already discussed arguably fit into the human growth and development category, since they focus on individual perceptions, feelings and preferences. The person needs to feel motivated, comfortable, and able enough to get involved. The

models that follow in the next section can be categorised as socialist or democracy theory-based, as the focus is more on power-relationships and citizen involvement.

1.6.2. Hierarchical models

This group of models are arguably the most frequently referenced in the literature – they describe involvement in terms of ascending levels. These models are essentially based on an assumption that different levels of involvement are related to concepts of power, and that greater levels of involvement are the most desirable. If we take Arnstein’s (1969) ladder of participation as the first example, being the most referenced in the literature, the language used suggests that different levels of power of professionals result in different levels of participation from the individual. As you will note from Figure 9., the lower levels are described as ‘non-participation’, the middle levels are described as ‘degrees of tokenism’, and the higher levels are described as ‘degrees of citizen power’.

Figure 9. Ladder of participation (Arnstein, 1969: p.217)



Arnstein’s (1969) focus is on power relationships between professionals (or decision-makers) and the individual. The bottom two ‘rungs’ of the ladder (non-participation) are described as having “been contrived by some to substitute for genuine participation. Their real objective is not to enable people to participate in planning or conducting programs, but to enable power-holders to ‘educate’ or ‘cure’ the participants” (p.217). This indicates that

Arnstein felt that certain methods of participation are about maintaining traditional power relationships. Arnstein argued that the middle rungs (Informing, Consultation, and Placation in ascending order) claim to be about involvement of the individual but individuals lack the power to ensure their views are included. Finally, Arnstein argues that those activities that are classed as ‘degrees of citizen power’ (Partnership, Delegated Control, and Citizen Control in ascending order) include at least an element of citizen power to make decisions (e.g. partnership allows the citizen to have the power to negotiate with professionals).

Arnstein’s (1969) model is arguably simplistic by assuming that citizens are either powerful or not. As Thompson (2007) concluded, the individual’s wishes and preferences about being involved are important, and therefore, those on the lower rungs of the ladder might be happy with that level of involvement. Arnstein (1969) acknowledges that the ladder is rather simplistic and it categorises both laypeople and professionals as either powerful or not, when it is probably more of a continuum. Arnstein states that “in actuality, neither the have-nots nor the power-holders are homogeneous blocs. Each group encompasses a host of divergent points of view, significant cleavages, competing vested interests, and splintered subgroups” (p.217).

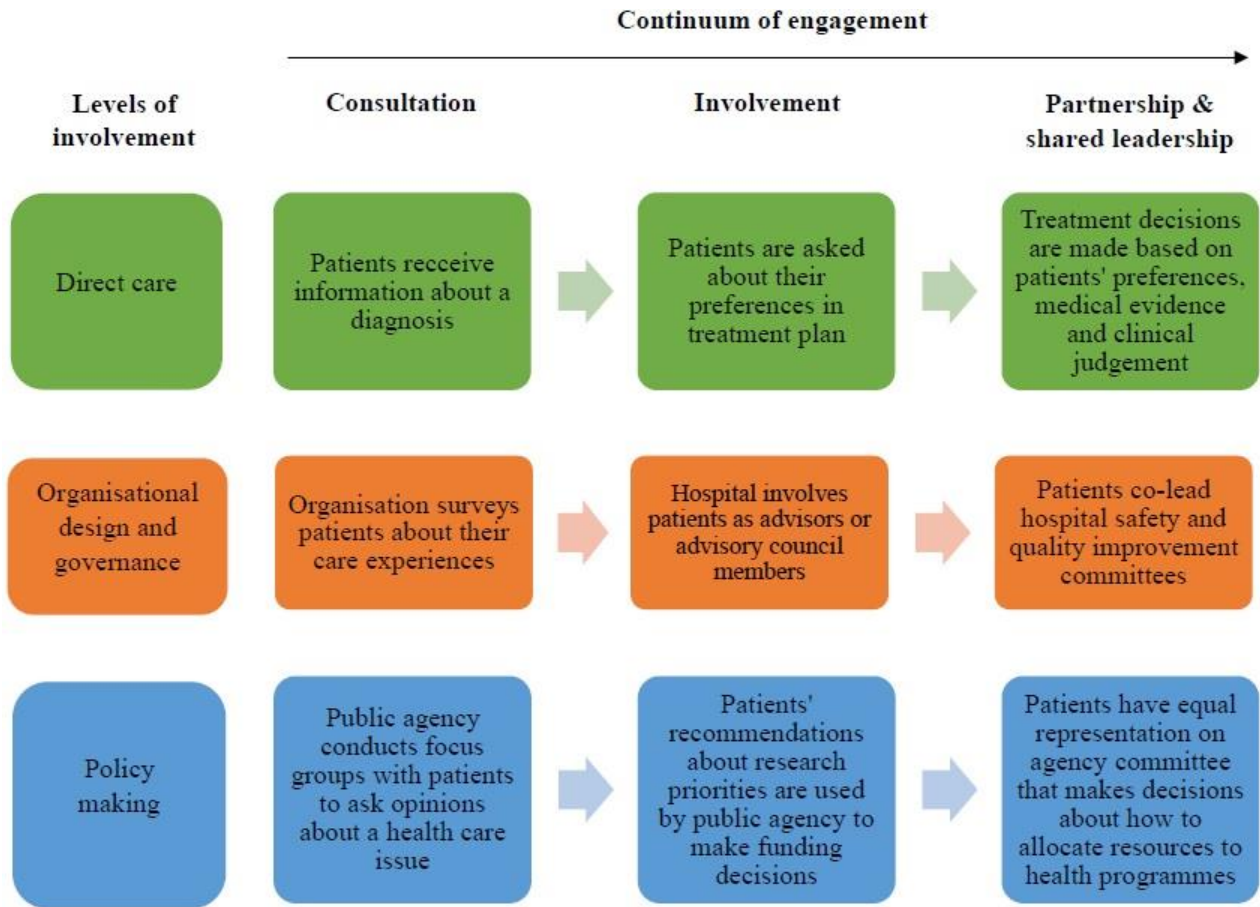
Furthermore, Arnstein’s (1969) ladder demonstrates an assumption that one should aspire to reach the higher rungs on the ladder – that citizen control is always desirable. Again, this is a rather simplistic view of participation that does not consider other factors such as context, and it may not always be practical to achieve the higher levels. It also highlights what has been called a ‘naïve bias’ in the literature. Contandriopoulos (2004) argued that research on PPI lacks critical scrutiny because participation is assumed to be an inherently good thing. As such, Contandriopoulos stated that this positive bias borne out of democratic ideologies inevitably leads to “negative conclusions” (p.321) in research. This is arguably true of Arnstein’s (1969) ladder concept. The language Arnstein uses (such as ‘manipulation’, ‘cured’, ‘power’ and ‘contrived’) indicates that levels of non-participation are not desirable and that higher levels of involvement should be achieved.

Other authors have also adopted the concept of levels of involvement, showing how influential Arnstein’s model has been. Hart (1992) adopted the same ‘ladder’ concept in the context of participation of children, and Goss & Miller (1995; as cited in Forrest et al., 2000) applied a similar concept to service user involvement in education. Hart (1992) used many of

the same labels as Arnstein for the levels of involvement (e.g. ‘manipulation’ at the bottom rung). Goss & Miller’s (1995; as cited in Forrest et al., 2000) model had five levels of involvement, in ascending order as follows: ‘closed model – no involvement’, ‘passive involvement’, ‘limited two-way communication’, ‘listening and responsive’, and ‘partnership’. Again, the assumption seems to be that the higher levels are more desirable, as indicated by the negative language used to describe the lower levels. The main focus is on power relationships between laypeople and professionals, without consideration of other factors that may also be at play. Furthermore, all three of these examples were developed conceptually rather than from empirical evidence, which makes the validity of the assumptions questionable.

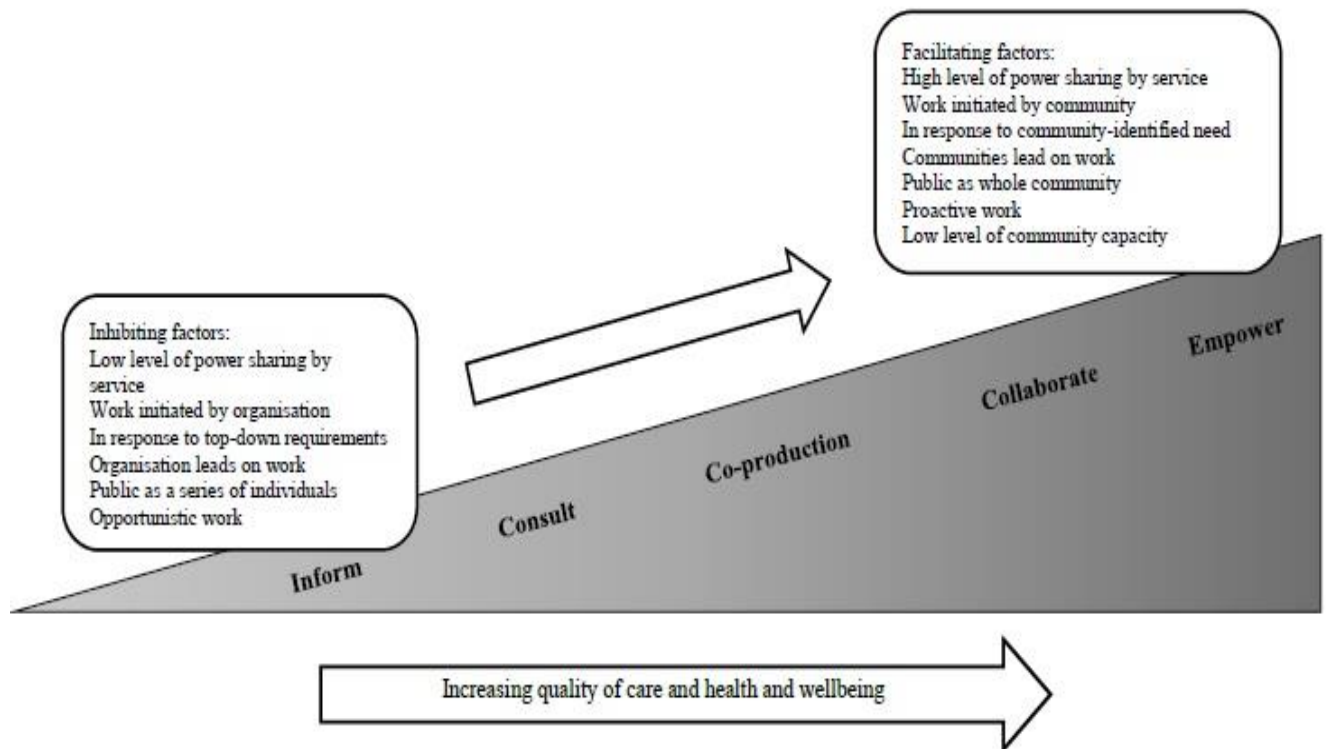
Another more complex model of PPI (or engagement as it is referred to) by Carman et al. (2013) considers there to be levels of involvement, as the previously described models do, but also takes into consideration some other influencing factors, as shown in Figure 10. It also suggests these levels of involvement can be placed on a continuum rather than necessarily in a hierarchy. The influencing factors cited are patient-specific (e.g. beliefs), organisation-specific (e.g. policies), and societal (e.g. social norms). However, the language used, whilst less negative than those models presented above, still appears to suggest the greater levels of involvement are more desirable, as they place patients in more powerful positions (e.g. co-lead). They also term the end of the continuum as ‘shared leadership’, again suggesting this is a position to aspire to.

Figure 10. A multidimensional framework for patient and family engagement in health and healthcare (Carman et al., 2013: p.225)



In a similar manner, Sallnow & Paul (2015) also adopt the 'ladder' concept in the context of end-of-life care, but again, have considered inhibiting and supporting factors, as shown in Figure 11. However, this model again appears to place higher levels of engagement as preferable by presenting the highest level as 'empowerment'. The positive language placed on the higher levels in this and the preceding models appears to suggest that these are the methods practitioners should aspire to. Furthermore, note the phrase "increasing quality of care and health and wellbeing" at the bottom of Figure 11, again reiterating their assertion that the higher levels are to be aspired to.

Figure 11. Spectrum of engagement in end-of-life care (Sallnow & Paul, 2015: p.234)



In these models, there appears to be an inherent preoccupation with notions of power and hierarchies which define the level of involvement. The negative language used in describing the lower levels of involvement suggests that these authors have made an assumption lower levels of involvement are undesirable. But as described in depth in the previous sections, PPI is multifaceted and has been found to be effective at various levels and in various contexts (e.g. Bovaird, 2007). As such, the models in this section have arguably been too simplistic to adequately convey a complex social phenomenon. Furthermore, rather than seeing individuals as purely powerful or not, the models in the next section focus on different role definitions and how this determines the type of involvement. There is no assumption that one type of involvement is necessarily better than another, and there is an acknowledgement that different levels and types of involvement are appropriate in different circumstances.

1.6.3. Models focusing on role definition

The models discussed in this section are different in that they focus on how the definition of the participants' and professionals' roles determines the type of involvement. Take, for example, Forbat et al.'s (2009) ideas about different interpretations of the patient

(see Table 8), which was developed from a review of existing literature and models. Forbat et al. (2009) argued that the type of involvement varies depending on how the patient is viewed. Specifically, they defined four possible interpretations of the patient: patient as consumer, patient as citizen, patient as partner and patient as researcher/evaluator. These roles imply very different ideas about what involvement is and should be.

As a consumer, the patient is a recipient of services and the type of involvement they have relates to their choice over a service or treatment. Viewing the patient as a citizen has different implications – instead of being a passive recipient of services, the patient is a member of society who has a valuable contribution to make to service decisions for the greater good of society. When a patient is viewed as a partner, they are more involved in decisions about their own care – viewed as offering a different kind of knowledge and experience to that of the professional, but of equal value to the professional’s medical and technical knowledge. Finally, the patient as a researcher/evaluator views them as a valuable contributor to evaluating services, practice, and standards. As Forbat et al. (2009) highlight, these interpretations are formulated from fundamentally different ideological drivers, similar to those defined by Dachler & Wilpert (1978) (see beginning of section 1.6.).

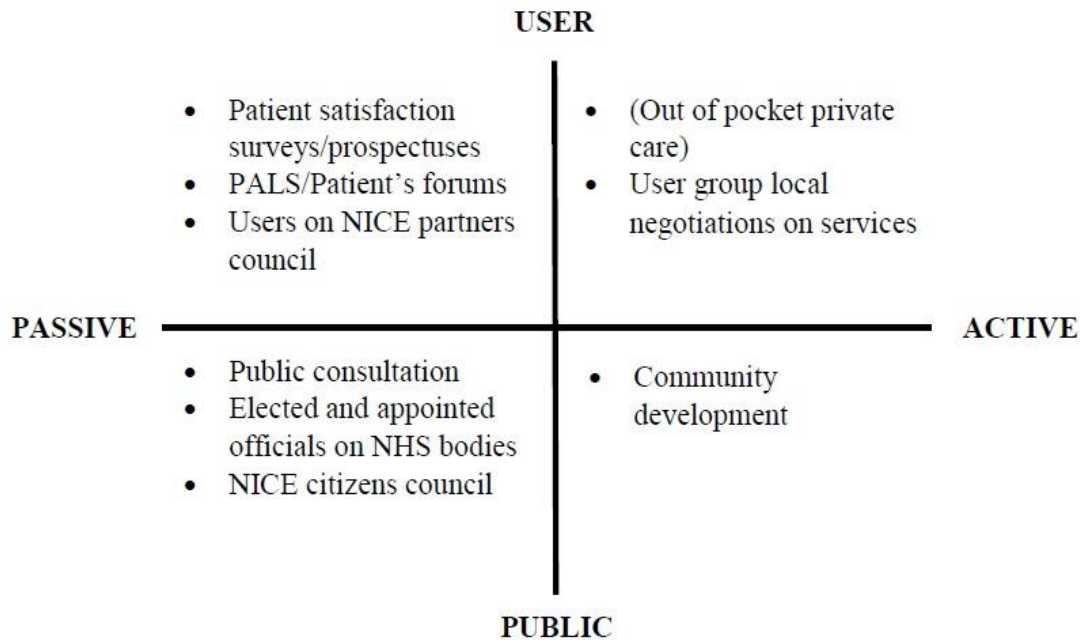
Table 8: Four models of involvement (Forbat et al., 2009: p.2548)

Who	What	Ideological drivers
Patient as consumer	Purchase or choice of service	Free-market economics
Patient as citizen	Policy and service planning	Social-democratic
Patient/carer as partner	Care practice	Experiential knowledge
Patient as researcher/evaluator	Co-research	Emancipation and empowerment

Harrison et al. (2002) take a slightly different approach in that they present types of involvement in four different categories. Each of the categories (shown in Figure 12) is defined by either ‘user’ or ‘public’ involvement, and either ‘passive’ or ‘active’ involvement. Harrison et al. (2002) argue that patients and the public are not synonymous and it should not be assumed that their interests will be identical. The public are different in that they may have no specific health knowledge or experience, and they may be more concerned with healthcare services from the perspective of a taxpayer rather than a potential or existing user. This

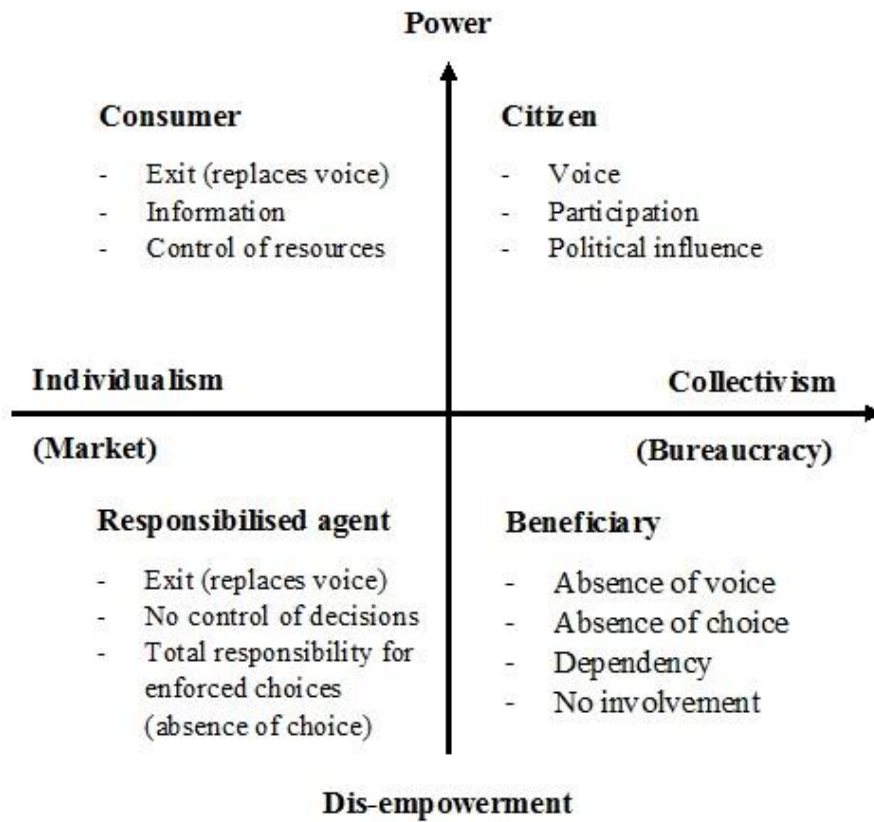
suggests Harrison et al. (2002) feel that methods of engaging with these groups should be different because they are different groups.

Figure 12. Typology of involvement (Harrison et al., 2002: p.65)



In a similar manner to Harrison et al. (2002), Fotaki (2010) conceptualised user involvement in terms of the roles of citizens versus consumers. In Fotaki's constructions (see Figure 13), however, there are two further roles examined of 'responsibilised agent' and 'beneficiary'. Responsibilised agents are consumers whom have limited choices designed by professionals. Beneficiaries are citizens whom benefit from services but have them imposed on them (e.g. welfare). Furthermore, Fotaki does not separate these roles completely and instead views them on a continuum, in that consumers can define themselves as citizens and vice versa. At either end of the spectrum, consumers exercise their power through choosing services (individualist), whereas a citizen is more concerned with the good of society (collectivist), but a person can be anywhere between these two. Also note that Fotaki cites the notions of power and disempowerment conveyed in Arnstein's (1969) and Hart's (1992) 'ladder' concepts. This differs from Harrison et al. (2002), whom did not attribute different methods of involvement to differing levels of power. Both 'consumers' and 'citizens' are deemed to be powerful, whereas 'responsibilised agents' and 'beneficiaries' are deemed to be disempowered in Fotaki's (2010) model.

Figure 13. User of public services in relation to various Government regimes (Fotaki, 2010: p.945)



Finally, Marent et al. (2015), whom argued there needs to be greater conceptualisation of PPI at an organisational level, also defined PPI based on roles of individuals (patients and roles in organisations) and functions in organisations (see Figure 14). Marent et al. (2015) conceptualisation differs from the others in this section in that it makes more explicit consideration of contextual factors. Furthermore, Marent et al. (2015) do not define different forms of PPI in hierarchical terms, as models in the previous section appeared to, recognising that PPI can work differently and serve different functions in different contexts, involving different types of people. There is no assumption that any form of PPI is less valuable than another and, as such, goes some way towards recognising the complexities of PPI in healthcare organisations. However, it should be noted this conceptualisation was based on literature reviews rather than empirical data.

Figure 14: Participatory lay roles and related issues and functions in health care organisations (Marent et al., 2015: p.837)

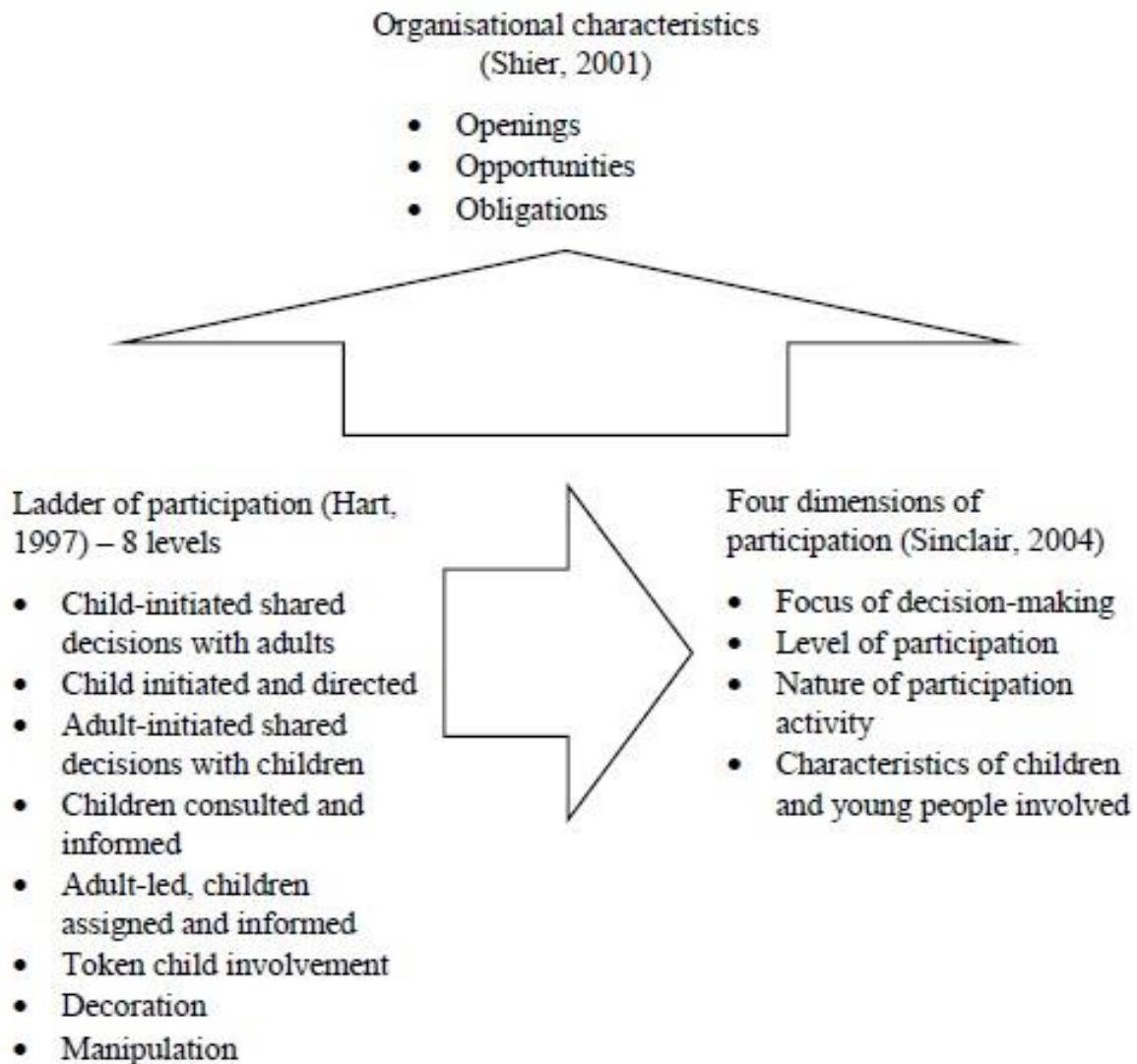
	Organisation	Environment
Operative level	Role: individual patient Issues: treatment and care Function of participation: facilitation of co-production	Role: patient's significant others Issues: treatment, care and aftercare Function of participation: support of co-production
Management level	Role: patient groups Issues: quality and integration of services Function of participation: observation/evaluation of internal processes	Role: community Issues: responsiveness to (neglected of new) needs Function of participation: realigning the organisation to (new) expectations and demands

These models that focus on how the individual's role and identity is defined as the key driver for participation raise an interesting issue that other models have potentially failed to recognise. An individual's identity and sense of role is key to the way they behave and conduct themselves around others, and therefore should be a key aspect of PPI models. But what these models do not convey are the varying contextual factors that may be at play. Again, these conceptualisations of PPI have been potentially over-simplified. The models in the next section attempt to explain the potential influencing effect of those wider factors.

1.6.4. Models on the wider aspects of participation

The models discussed in this section expand concepts beyond individual patient-practitioner consultations and levels of involvement in hierarchical form. These models take greater consideration of external factors that influence involvement, such as organisational structures and political drivers. The first example is from Day (2008), who combines three ideas about participation together, as shown in Figure 15. In the context of children's participation, Day (2008) combines Hart's (1992) ladder concept, Shier's (2001, as cited in Day, 2008) ideas about organisational characteristics, and Sinclair's (2004, as cited in Day, 2008) 'dimensions' of involvement. The combination of these models demonstrates a broader thinking about what participation is and what influences it. This has perhaps more value than the three models in isolation. Furthermore, although Day (2008) refers mainly to children's participation, the ideas can likely be applied to numerous other settings and contexts.

Figure 15. Elements of children's participation (Day, 2008: p.3)

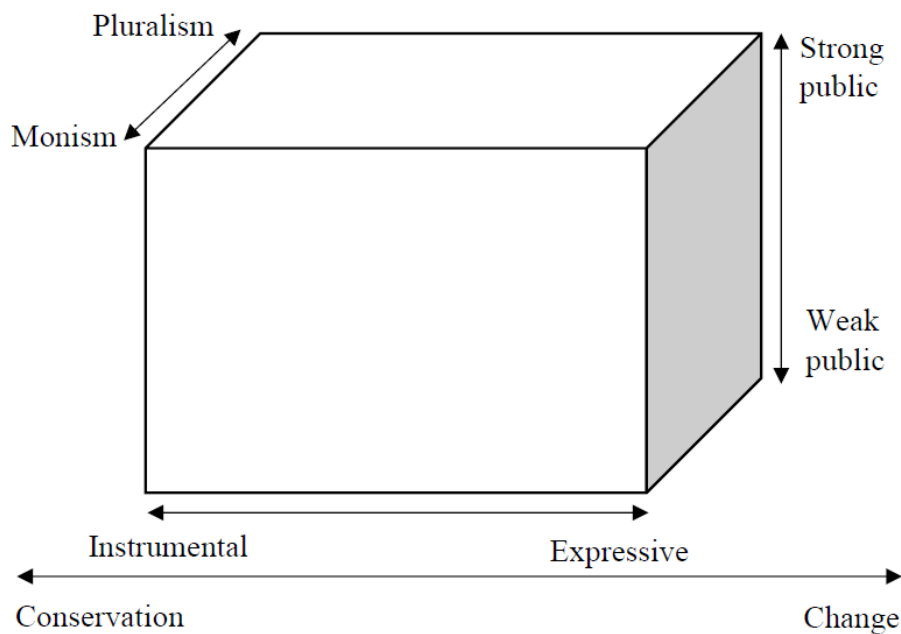


Another model that more explicitly references contextual factors is that of Abelson (2001). Abelson argued that participation (the methods of, form, tone, intensity, quantity, and initiation) is influenced by three groups of factors: pre-disposing influences (social and structural factors of the community), precipitating influences such as interest groups, and enabling influences such as having a participatory culture in the organisation. Their model of contextual factors was based on the results of four case studies of PPI in healthcare in Canada. They take a deterministic view, describing participation as a 'dependent variable' determined by the influences already described. Unfortunately, whilst this model has captured an array of contextual factors, it does not consider individual factors, or wider contextual factors such as political influences. As such, this model is, again, potentially over-simplified.

More recently, Gibson et al. (2012) argued that PPI should be conceptualised in terms of ‘knowledge spaces’, incorporating the role of social, political and cultural influences. They proposed four dimensions within which PPI can be analysed: ‘expressive to instrumental action’, ‘weak to strong publics’, ‘monism to pluralism’, and ‘conservation to change’ (p.536). They argue that each of these dimensions are on a continuum, and that if patients and laypeople are categorised at one end of any of these dimensions and professionals at the other, conflict will occur. They point to the typically ‘expressive’ forms of action patients take based on their lived experiences, versus the ‘instrumental’ goal-based and rational actions of professionals. They describe ‘weak’ and ‘strong’ publics – the public is not one group but several groups unified by a particular characteristic (e.g. gender) and some groups have a stronger voice than others.

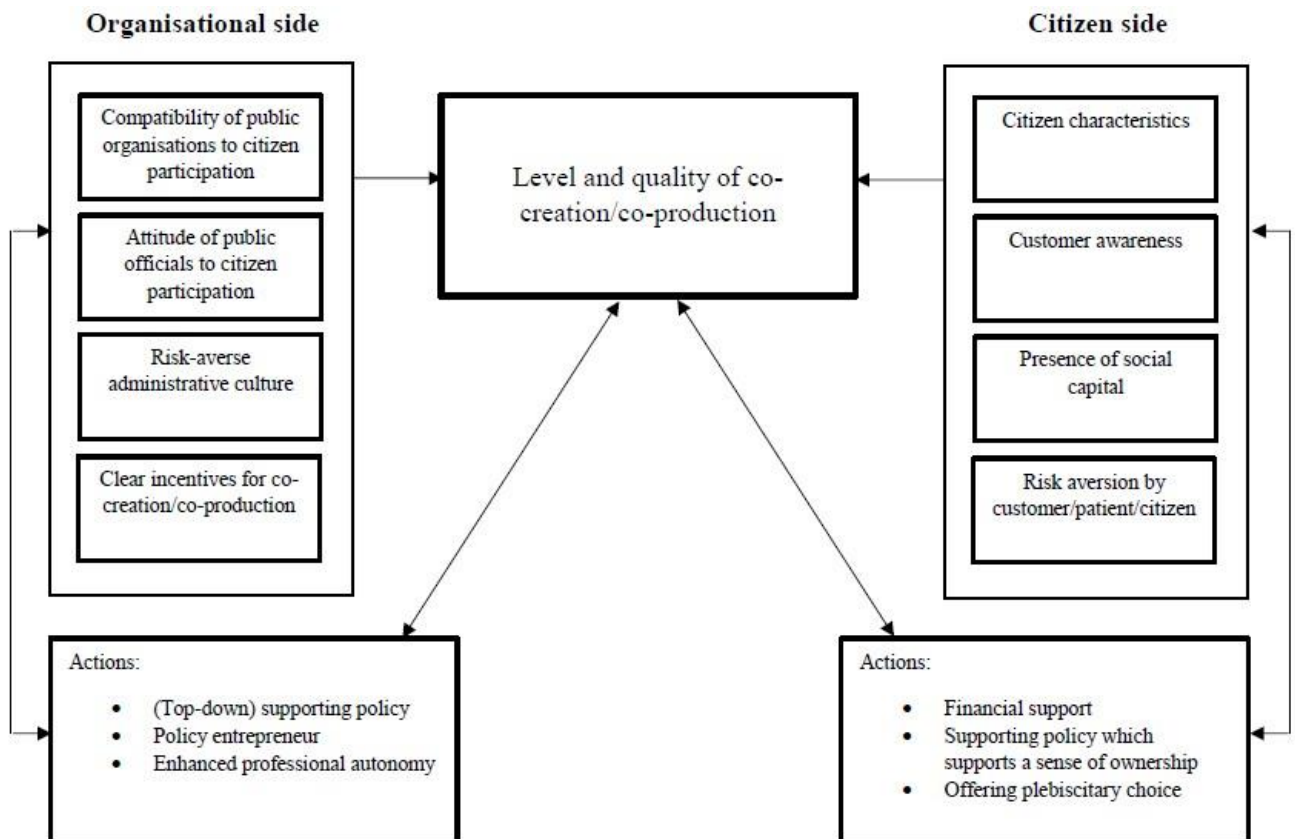
They also indicate that there can be varying degrees of opportunities for PPI (monism versus pluralism). Finally, they argue that, cutting across these three dimensions already described is the fourth dimension of ‘conservation to change’, referring to the tendency for some to be resistant to change in favour of conserving predictable systems, whereas others embrace and look for systematic change. They propose that these four dimensions define ‘knowledge spaces’ (see Figure 16), which provides a useful way of analysing PPI initiatives. This framework was even demonstrated to have practical applicability when utilised in a series of workshops with PPI participants, whom were able to describe PPI in these terms (weak and strong voices, having few or many ways to get involved, addressing organisational or public concerns, and the organisation’s willingness to change) (Gibson et al., 2017).

Figure 16: A four-dimensional view of knowledge spaces



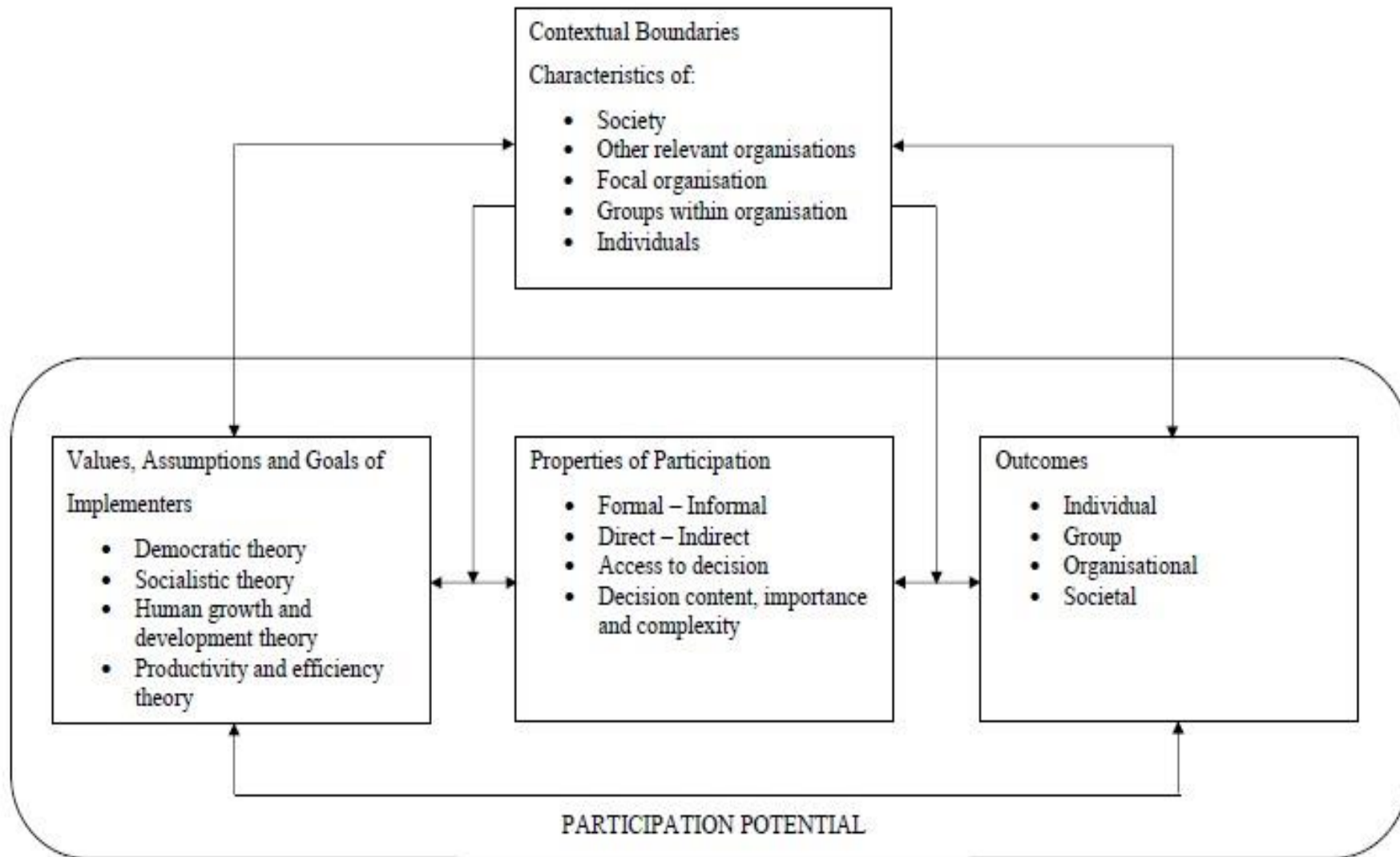
The next model (though not described as such by the authors Voorberg et al., 2015) has been developed from a systematic review of co-production in public services (most of which was in the healthcare industry). It identifies organisation-level and citizen-level influential factors on the quality and level of co-production. At the organisational level, they identify the following influential factors: ‘compatibility of public organisations with citizen participation’ (referring to having defined structures and mechanisms for participation); ‘open attitude towards citizen participation’; ‘risk-averse administrative culture’ (leading to an aversion to citizen participation); and ‘presence of clear incentives for co-creation’. At the citizen-level, they identified the following influential factors: ‘citizen characteristics’ (such as skills); ‘customer awareness/feeling of ownership’; ‘presence of social capital’; and ‘risk aversion by customers/citizens’. They further identify a number of actions to overcome barriers to participation: (top-down) supporting policy, policy entrepreneur and enhanced professional autonomy at the organisation-level; and financial support, support policy that emphasises sense of ownership, and offering plebiscitary choice at the citizen-level. Figure 17 shows the influence of these factors on the level and quality of co-production.

Figure 17: Influential factors of co-production (Voorberg et al., 2015: p.1344)



The final model discussed here is that of Dachler & Wilpert (1978). This model has similar aspects to all those discussed so far, but it is different in that it combines all these complex factors. Figure 18 shows a depiction of how these different factors relate to one another. As discussed earlier, Dachler & Wilpert suggested that participation is driven by one of four ideologies: socialism, democracy, human growth and development, and productivity and efficiency. They also suggested the type of participation depends on the outcomes intended and the contextual boundaries within which they operate. The combination of these factors, along with the characteristics of the participation itself, defines the potential effectiveness of participation. They further add that their model of participation presents it as a “multidimensional, dynamic social phenomenon” (p.1). However, whilst this model has considerable potential application, it is important to note that the authors developed this model from a literature review rather than from empirical evidence – something that the authors themselves recognise as a limitation. It is also now very dated at nearly 40 years old.

Figure 18. Model of Participation (Dachler & Wilpert, 1978: p.2)



1.6.5. The case for a change in our conceptualisations of PPI

This literature review has shown that PPI is a contentiously debated topic regarding its purpose and effectiveness. But debate and research has frequently been without significant theoretical contribution (Staniszewska, 2009), and there remains a “conceptual vagueness” (Tambuyzer et al., 2011: p.140). Some have attempted to examine and model PPI, but have potentially been held back by others’ (or indeed their own) ideological assumptions (Contandriopoulos, 2004). As many would argue PPI is an inherently good thing, it is difficult to hold one’s head above the parapet and claim it is ineffective or has no valid purpose. Therefore, there has been a lack of critical examination of PPI (Contandriopoulos, 2004; Mockford et al., 2012; Pizzo et al., 2014). It is these ideological restraints that have prevented robust examination (and therefore, robust theory) from developing. This further leads to a lack of theoretical conceptualisation that resonates with practitioners conducting PPI work.

As discussed in the previous sections, many models of PPI have been relatively simplistic. They have primarily focused on micro-processes of PPI (the ‘how’) and relationships and interactions between professionals and laypeople (the ‘who’), with only some recognition of ideological drivers and contextual factors. Indeed, Gibson et al. (2012) point out that analysis and conceptualisations of PPI should incorporate “cultural, political and social dimensions of a diverse and unequal society and sector” (p.535). Rose (2014), and more recently Rowland et al. (2017), similarly argued there needs to be greater conceptualisation of PPI in terms of political and ideological underpinnings, such as emancipatory perspectives of participation and parallels with feminist theories.

Other models have attempted to frame different types of participation with some references to different contexts and situations, but these have, again, been potentially oversimplified. Those models focusing on role definitions have also missed a key role out of the equation – the role of facilitators (though Marent et al. (2015) do point out the varying roles in organisations). These theorists appear to have made an assumption that all professionals can be defined in the same terms as one homogenous group. Others focus on the role identity of patients and the public with limited consideration of professional identities. In reality, there are multiple roles in PPI activities and, equally as important, multiple roles in activities outside of the PPI activities (e.g. governance structures), where a great deal of decision-

making is likely conducted. Frith et al. (2014) make the point that “theory needs to catch up with practice” (p.18), for the same reasons argued here.

Furthermore, as already discussed, most models have been developed from either literature reviews or small case studies. Many of the case studies themselves have involved observations of the micro-processes of PPI activities, hence, the focus of some models on only the process. This PhD research is different in that it examines three organisations as whole case studies, with the aim of examining PPI mechanisms across the organisation rather than micro-processes, which few studies have done (see Croft et al., 2016, for one example that focuses on commissioning organisations). Data collected were considered within the context of wider organisational structures and processes. This has allowed for a more comprehensive analysis of PPI in practice. This is what has been needed to assess the impact of PPI more thoroughly, considering all key factors: relationships and interactions between professionals, facilitators, and patients/laypeople; contextual factors, such as organisational structures and policies; drivers for PPI (internal and external to the organisation); methods of PPI; and logistical and practical factors.

1.6.6. Summary and research aims

The literature has highlighted how complex PPI can be. There are a multitude of influencing factors, varying perspectives from different stakeholders, and a lack of agreement on what constitutes effective PPI. Existing models of PPI have seemingly over-simplified what is a multifaceted social phenomenon, or haven't accounted for wider contextual factors. As such, the present research set out to examine PPI in a range of contexts, exploring individual perspectives and practical barriers and facilitating factors, as well as external influencing factors. The key rationale was that, in order to develop a more comprehensive understanding of PPI, it was necessary to collect empirical data in different contexts and develop a conceptual framework from the data, rather than from reviewing existing literature.

Below are the key aims of the research. The aims of the research are notably broad; however, this was necessary to ensure the development of a conceptual framework encapsulated the complexities of PPI. In other words, as the PPI literature has highlighted a multitude of complex themes that points to a lack of precise definition, broad aims were thought to be necessary. No definition of PPI from the literature was applied to the data collected. Instead, the aim was to allow the data to drive the development of a conceptual

framework. Full details of how the research was carried out and the rationale for the chosen methodological approach will follow in the Methodology.

1. Identify PPI mechanisms in whole healthcare organisations, rather than only individual PPI processes, to explore contextual factors.
2. Examine the relationships and interactions of a range of stakeholders, and explore motivations and identity perspectives of these individuals.
3. Explore the outcomes and impact of PPI within large healthcare organisations. (Outcomes and impact as defined by the individuals involved in the study.)
4. Develop a conceptual framework of PPI that maps the connections between the multiple factors at both the micro and macro levels.

2. Methodology

The following sections describe the methodological approach taken in examining PPI in three healthcare organisations, as well as the methods of data collection and analysis in practice, and ethical considerations made. The research aims were set out in the previous section – what follows will describe how these aims were achieved in practice and the theoretical underpinnings of the methodological approach.

2.1. Methodological approach and theoretical underpinnings

The research involved gathering qualitative data from three healthcare providers as case studies of PPI, and analysing this data in a manner that draws out themes from the data to develop conceptualisations of PPI. Qualitative research is by its very nature interpretivist, concerned with the rich experiences of people in various social contexts (Coyle, 2007). It assumes there is not one fixed reality, and that it is instead socially constructed and continuously evolving. Qualitative methods of data collection and analysis have become increasingly popular in organisational research since the 1970s (Bryman, 1989). Social scientists have more frequently rejected traditional ‘scientific’ quantitative methods because of their distance from ‘real life’ and their lack of capability to explore complex social phenomena in their natural settings (Coyle, 2007; Gough & McFadden, 2001). In previous sections of the thesis, the complexities of PPI have been highlighted from the literature review. As such, it was deemed important to utilise an interpretive qualitative approach to examine the complexities of this social process.

It should be noted that a quantitative methods approach was carefully considered for this research before being determined as inappropriate for the research aims. In the literature on PPI, several models and theories about PPI activities and processes have been developed – some which focus on the interaction between professional and patient/layperson (e.g. Entwistle & Watt, 2006), and some which consider contributing factors for wider citizen involvement in public services (e.g. Abelson, 2001). Whilst reviewing the literature, the possibility of ‘testing’ some of these ideas and models was considered.

However, upon reflection and review of models and theories available in the literature, it became apparent that existing models were potentially too simplistic, as already discussed in sections 1.6.1-7. Although one model that presented a more explicit acknowledgement of

these issues was identified (Dachler & Wilpert, 1978), their framework was based on reviews of a range of studies (where access to raw empirical data would have been limited), and is now nearly 40 years old. A great deal has changed in healthcare since this time led by numerous legislative changes (as described in section 1.1.4), and attitudes of both service users and healthcare staff may well have changed considerably too. It is for these reasons that the current research focuses on returning to empirical data to examine the multifaceted nature of PPI to build on and challenge prior conceptualisations of PPI.

This research was concerned with understanding how PPI operates in different healthcare providers (i.e. different contexts), what meanings are attached to PPI by different stakeholders, and the impact PPI has on organisational decision-making. The aim was to develop a conceptual framework that attempts to explain this complex social process with greater emphasis on contextual factors. As such a qualitative approach to collecting data was necessary, particularly to examine the context. Surveys (e.g. Alborz, 2002; Crawford et al., 2003) have been done before to look at organisations' PPI processes, but have revealed limited findings (i.e. they have only been able to access the 'what' – what methods of PPI exist, and not more complex questions of 'how' and 'why').

Understanding the social context surrounding this social process was of primary importance in this research. Johns (2006) argues that “context can have both subtle and powerful effects on research results” (p.386-387), and that much organisational research does not pay due attention to the impact of context, leading to “tenable inferences” (p.387). As such, qualitative research methods appear to offer advantages over quantitative methods, as observational methods were needed to consider the context. Coyle (2007) states “I tend to view context in terms of the social systems and feedback loops in which an individual is embedded and through which they make sense of, construct and are constructed by their worlds” (p.17). Exploring these social systems in their real-life setting (i.e. workers within their employing organisations) was deemed to be important for examining PPI. In addition, a qualitative methodological approach offers more flexibility, which is also important for examining the context. In PPI literature, a study by Leppo & Perälä (2009) found context to be an important factor in how PPI works in practice, though their study compared two individual services, and not the wider organisations within which they operated. Examining the organisational context adds nuances to existing literature on PPI.

Furthermore, this research takes a pragmatist perspective. The everyday sense of the term ‘pragmatism’ is “a matter-of-fact approach to problem-solving”; and when expanded to the philosophy of pragmatism, “pragmatists address philosophical questions...by arguing that these questions should be addressed by drawing upon the resources offered by our practices” (Bacon., 2012: p.1). One might argue that, by taking a pragmatist perspective, it would not be possible to extrapolate the findings and apply them to theory because pragmatism only addresses a specific problem in a specific context. However, Bacon cites Dewey’s (1908) response to such criticism, who argued that “everything of a practical nature is regarded as ‘merely’ personal, and the ‘merely’ has the force of denying legitimate standing in the court of cosmic jurisdiction” (Bacon, 2012: p.5). Given that PPI is a complex social process, or rather a series of processes in the organisational context, to examine it in its entirety requires consideration of the practical application in the real-life setting.

Finally, this research took a critically evaluative approach in examining the concept of PPI. PPI has, in the past, been arguably idealised to such an extent that it becomes untouchable by critical research (Contandriopoulos, 2004). This research attempted to explore PPI without a pre-defined view of what PPI should be. Questions about the nature of PPI and how it operates in different contexts were asked; but the questions of why it happens and what purpose it has were also asked. PPI has been argued to be rooted in the fundamental principles of a democratic society – citizens being actively involved in the institutions that serve them (Milewa, 2004). But does PPI make a difference, and indeed, is it capable of making a difference? And how is the purpose defined, as perceived by different stakeholders? These questions were attempted to be answered through a comparative case study approach.

As already alluded to, whilst the purpose of this research was to contribute to theory by returning to empirical data to develop a conceptual framework, several key factors identified from the literature review were still pertinent to this research. In other words, this research acknowledges that the literature already presents a wealth of theoretical understanding of various *aspects* of PPI, but that the complexities have not been fully addressed. Table 9 provides a summary of the factors identified from the literature, how they were evidenced through data collection in the present study, and the rationale for how and where data were collected. The final conceptual framework will include, but will not be limited to, the themes below. Participant group names have been included in the table – full details of all participants will be included in section 2.6.

Table 9: Identified factors from literature and existing models

Factor	Data collection	Participants
Power conflicts	Observations of activities where professionals engage with patients and the public around decision-making, evaluations of services, etc.	Those responsible for PPI, some clinical staff whose role included an element of PPI, and laypeople/service users who were engaged by the healthcare provider.
Interpretation of PPI by different stakeholders	Interviews and informal conversations with key stakeholders about their interpretation of what PPI is, how it should be done and what the desired/actual outcome is. Their motives for taking on the role were also explored.	Both professionals and laypeople were invited to take part in interviews.
Role identity	Interviews with both professionals and laypeople were utilised to explore how people interpret their role with regards to PPI and what motivates them to do so.	As above.
Professionalisation of laypeople	Observations of activities where professionals and laypeople meet, and interviews with both groups. Behaviours of the laypeople were observed alongside professionals to identify any similarities.	Observations of the laypeople, as well as perceptions of both groups through interviews.
Political drivers	Evidence from observations, interviews and document reviews were utilised to explore the impact policy has on how PPI works.	Both professionals and laypeople through observations and interviews.
Organisational structures	Documents were reviewed to understand different structures, and interviews served as another data collection method to include detailed explanations of organisational structures.	Professionals only (as laypeople were unlikely to have in-depth knowledge about organisational structures).

Organisational priorities/commitment	Observations, interviews, and document reviews provided evidence of these. Policies and strategies published by the case sites were examined to understand the officially stated purposes of PPI.	As above.
PPI processes and methods	Types of PPI were explored mainly through observations, though some documents and interviews supported data from observations.	Observations of and interviews with both professionals and laypeople.
Outcomes	Interviews with professionals and laypeople to examine perceptions of impact as well as identify specific outcomes. As observations were of PPI activities, it was not possible to physically observe outcomes, though some action plans were mentioned during observations.	As above.

2.1.1. *The ‘validity’ of the methodological approach*

Qualitative approaches to data collection and analysis have at times been criticised for not having the same ‘validity’, ‘reliability’, and ‘generalisability’ of quantitative methods. Easterby-Smith et al. (2012) summarise (see Table 10) how those from differing epistemological standpoints answer the traditional concerns of validity, reliability and generalisability in research. Although the present research has not been defined as ‘social constructionist’, the questions in the fourth column of Table 10 have the closest application. Answering each question individually, ‘Does the study clearly gain access to the experiences of those in the research setting?’ – as all participants interviewed and observed were central to PPI processes in each organisation the data offered strong ‘validity’. Secondly, ‘Is there transparency about data collection and interpretation?’ – descriptions of how all data were collected and interpreted in practice are detailed in section 2.2., which demonstrates the research is ‘reliable’. Thirdly, ‘Do the concepts and constructs derived from this study have

any relevance to other settings?’ – as the findings were mostly consistent across three different healthcare providers, it suggests the same issues are likely to be present in other healthcare providers, therefore offering ‘generalisability’, or ‘resonance’ as is the chosen term here, to other settings.

Table 10: Four perspectives on validity, reliability, and generalisability (Easterby-Smith et al. 2012, p.71)

Viewpoint	Strong positivist	Positivist	Constructionist	Strong constructionist
Validity	Do the measures correspond closely to reality?	Do the measures provide a good approximation of the variables of interest?	Have a sufficient number of perspectives been included?	Does the study gain access to the experiences of those in the research setting?
Reliability	Has the design eliminated all alternative explanations?	Will the measures yield the same results on other occasions?	Will similar observations be reached by other observers?	Is there transparency about data collection and interpretation?
Generalisability	To what extent does the study confirm or contradict existing findings in the same field?	How probable is it that patterns observed in the sample will be repeated in the general population?	Is the sample sufficiently diverse to allow inferences to other contexts?	Do the concepts and constructs derived from this study have any relevance to other settings?

Moving away from terms of ‘validity’, ‘reliability’, and ‘generalisability’, Tracy (2010) suggests there are 8 key markers of good qualitative research: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, good ethics, and meaningful coherence, as shown in Table 11. The present research meets these criteria in various ways, also shown in the third column of the table.

Table 11: Eight “Big-Tent” Criteria for Excellent Qualitative Research (Tracy, 2010: p.840)

Criteria for quality (end goal)	Various means, practices, and methods through which to achieve	How present research meets criteria
Worthy topic	<p>The topic of research is:</p> <ul style="list-style-type: none"> • Relevant • Timely • Significant • Interesting 	<p>The present study is a “worthy topic” because it is a very “significant”, given its political and moral implications, and the time in which this study was conducted was “timely” as renewed pushes for PPI had recently occurred following new legislation (Health & Social Care Act 2012). It is a topic that also attracts attention in both the academic and political arenas, and can therefore be deemed “interesting”.</p>
Rich rigour	<p>The study uses sufficient, abundant, appropriate, and complex:</p> <ul style="list-style-type: none"> • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes 	<p>This study also had “rich rigour” in that it developed “theoretical constructs” from “data and time in the field” in differing “contexts” and through carefully considered iterative “data collection and analysis processes” (which will be described in detail in sections 2.2. and 2.3.).</p>
Sincerity	<p>The study is characterised by:</p> <ul style="list-style-type: none"> • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges 	<p>The study also had “sincerity” in that the detailed descriptions provided in section 2.2. about data collection methods and its challenges show “transparency”, and a reflexive piece in section 4.1. demonstrates “self-reflexivity” about personal values and biases prior to conducting this research.</p>
Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> • Thick description, concrete detail, explication of tacit (contextual) knowledge, and showing rather than telling • Triangulation or crystallisation • Multivocality 	<p>This study offers “credibility” by providing “thick description and concrete detail” about the complexities of PPI, and by conducting numerous data collection methods for “triangulation” of richer and more varied data. This study also demonstrates further credibility through “multivocality” – the</p>

	<ul style="list-style-type: none"> • Member of reflections 	examination of multiple participant viewpoints.
Resonance	<p>The research influences, affects, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> • Aesthetic, evocative representation • Naturalistic generalisations • Transferable findings 	It is expected that the study will have “resonance” with readers as the findings are “transferable” to other healthcare providers and potentially other public services. The research has already influenced practice in two of the case sites (see section 4.12.1.).
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically 	This study does also make “significant contributions” for two major reasons: “conceptually/theoretically”, as the outcome of the data analysis is a conceptual framework of PPI; and “practically”, as two case sites have already used recommendations to change practice. The research also contributes “heuristically” to the field in that it proposes further lines of inquiry for the wider research community (section 4.12.).
Ethical	<p>The research considers:</p> <ul style="list-style-type: none"> • Procedural ethics (such as human subjects) • Situational and culturally specific ethics • Relational ethics • Exiting ethics (leaving the scene and sharing the research) 	As with all human studies, a full ethics review process had to occur. An ethics application had to be submitted Loughborough University and the NHS Research Ethics Committee. As such, this study was “ethical” and full details of the ethical considerations have been provided in section 2.7.
Meaningful coherence	<p>The study:</p> <ul style="list-style-type: none"> • Achieves what it purports to be about • Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	Finally, the study has “meaningful coherence” in that the research achieved its research aims (set out in section 1.6.6.) using the most appropriate methods (section 2.2.), and it connects and contributes to the wider literature, as demonstrated in the Discussion sections.

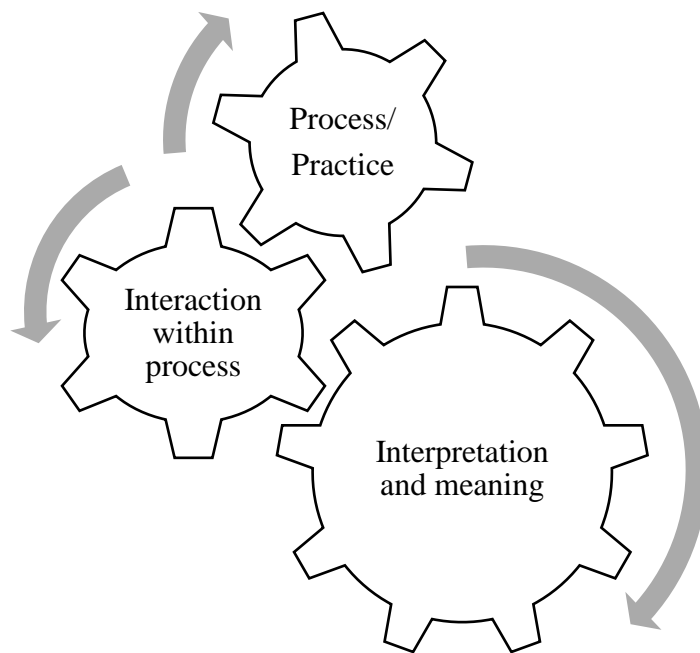
2.2. Methods – data collection

This research takes a case study design approach, in that three different organisations were compared qualitatively with regards to methods and processes of PPI, accounts and perspectives of key stakeholders, and organisation-specific barriers and facilitating factors. The aim was to compare how these three very different organisations involve patients and the public in decision-making and what outcomes occur as a result. Yin (2009, p.18) provides the following definition of case study research, that illustrates the rationale for conducting case study research in this study:

“A case study is an empirical inquiry that: investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident.”

As PPI is a complex social process it needed to be studied in its real-life context (Johns, 2006), drawing upon multiple sources of evidence in each site. Within each case site, numerous types of data were collected. The initial data collection method was to observe PPI activities within the organisation and the people responsible for PPI. Essentially, the researcher was within the organisation for a period of around one year in total (though not continuously). As such, the research utilised techniques from longitudinal ethnography. The research was partially reminiscent of an ethnographic approach in that several groups and sub-groups were joined and observed. This was in accordance with Hammersley and Atkinson’s (2007) description of ethnographers that they gather “whatever data are available to throw light on the issues that are the emerging focus of inquiry” and this is done through “participating, overtly or covertly, in people’s daily lives for an extended period” (p.3). To further illustrate why a case study design was most suitable, Njie & Asimiran’s (2014) “3 prime tasks in case studies” (Figure 19) show how interacting (as a researcher) with the “process” of PPI allows for a more detailed exploration of this complex social phenomenon.

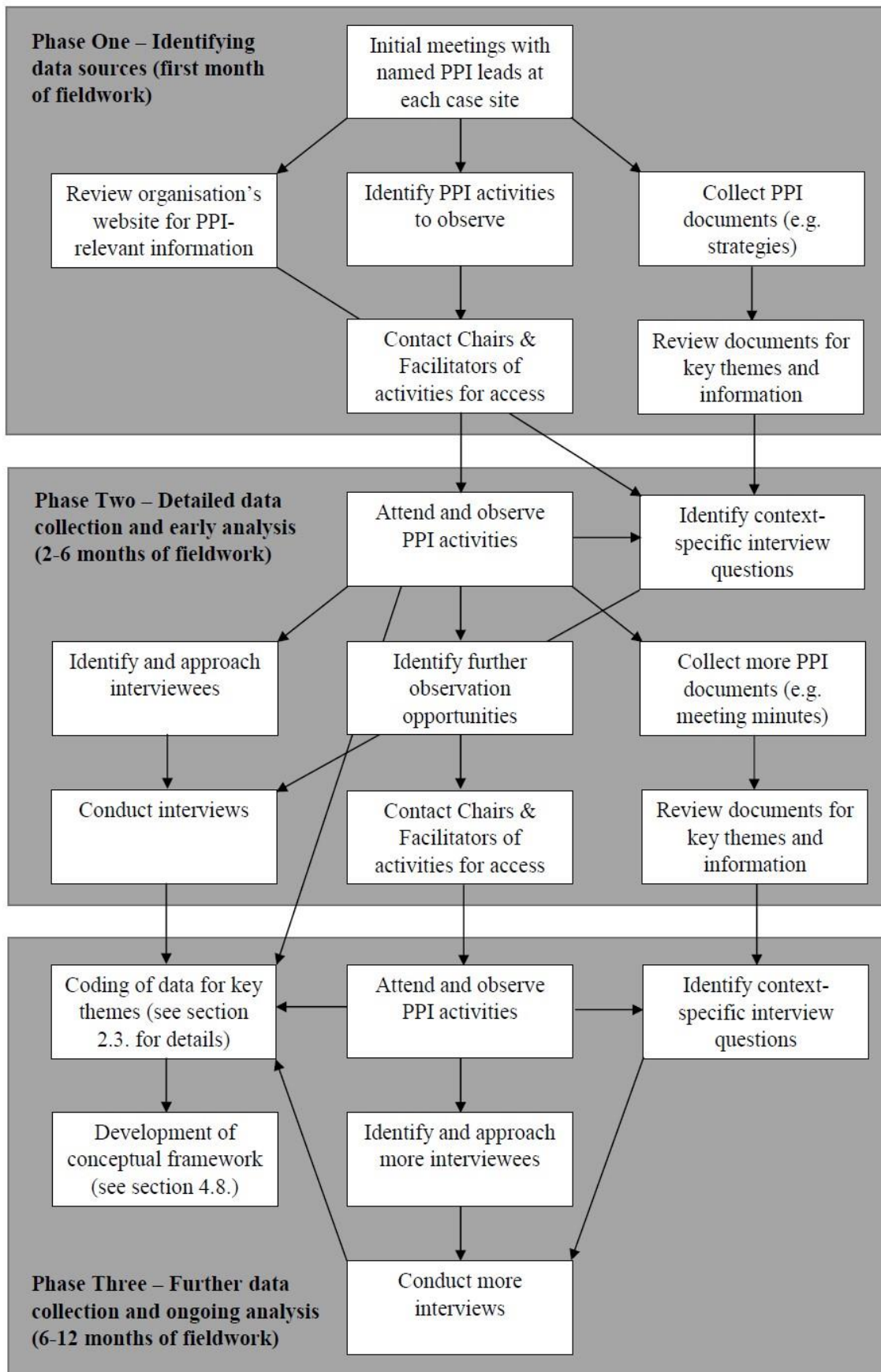
Figure 19: Three prime tasks in case studies (Njie & Asimiran, 2014: p.39)



In practice, ‘participating’ meant following a group’s activities relevant to PPI, and having conversations with participants informally (before or after observations), and more formally (through semi-structured interviews). In addition to these methods, documents from within the organisation were reviewed where relevant (e.g. PPI strategies). In-depth interviews were conducted with both professionals whom had some role in PPI, and laypeople who got involved in these activities. These methods were chosen as the most appropriate way in which to develop a conceptual framework inductively. The data collected throughout the year from each organisation was continuously reviewed and analysed to develop several iterations of a framework (the data analysis process will be described in detail in section 2.3.).

Detailed descriptions of each of the methods will be described in more depth individually in the next few sections, but by way of a summary of the data collection process, the chart in Figure 20 shows how data were collected, at what stage, and from what source.

Figure 20: Data collection and analysis process



2.2.1. Observations

In terms of the approach to observations, no template or pre-defined framework (in the form of a checklist, for example) was applied. Instead, the aim was to capture the verbal and physical contents of the activities (i.e. spoken word and materials used in the activities); the behaviours of and interactions between participants (i.e. verbal interactions, facial expressions, tone, etc.); the physical environment and layout (e.g. where people sit in relation to one another); and the general tone and mood of the activity. This was captured through note form with some visual diagrams included to reflect specific content of the meeting or activity, and to represent the layout and participant positions (e.g. seating plans).

Tape or video recordings were not made, as this was one of the major ethical considerations (see section 2.7.). It was also deemed to be impractical given that all activities observed involved at least 5 people, which would have been very difficult to transcribe. In total, 51 meetings and activities were observed (see Table 12 for details). Observations totalled 94 hours, with each individual activity lasting between 1 hour and 3 hours. Note that a much smaller number of activities were observed in the social enterprise (SE). This was because it was a much smaller organisation, having fewer activities available to observe. Full details of all three case sites will be provided in section 2.5.2.

Table 12: Types of activities observed

Observation type	MHT	SE	AHFT
Focus Group		2	2
Event			2
Committee/Panel		7	3
Project group	5		3
Governance meeting	11		11
Board meeting	1		1
Totals	17	9	22

Observations arguably have the potential of encouraging participants to take on ‘socially desirable’ behaviours and language that is different from their everyday behaviours. This effect is sometimes referred to as the ‘observer effect’ or ‘researcher effect’ (Monahan & Fisher, 2010). In this research, several groups were observed over a lengthy period (each group or project was observed for at least 5 months, with some observed up to a full year).

This meant that, in practice, the researcher became a familiar person. This allowed participants to become accustomed to the researcher's presence and continue with their activities without disruption. There were no evident changes in behaviours or language and tone over time, suggesting that participants had not attempted to modify their behaviour due to being observed. If they had modified their behaviour at the beginning of the research, it is unlikely they would have been able to maintain those behaviours for the lengthy period of observations. As such, the argument here is that any potential 'observer effects' were not evident.

One possible explanation for why participants appeared to continue to behave as they would likely do normally was because of the nature of working in the public sector – professionals working in public services are arguably accustomed to external observation due to the nature of their work (for example, being observed as part of inspections). It is possible that this may have been very different in a commercial industry where business professionals may have seen it as their duty to protect certain aspects of practice from external observation, protecting their commercial interests. Furthermore, given the care and passion these individuals had for their involvement and role in PPI (as described by participants during interviews), it could be argued that they would likely not wish to disrupt the ordinary conduct of the activities by behaving any differently to their normal practice.

Having said this, even if 'observer effects' had occurred, the nature of ethnographic research approaches means that they are often "unavoidable in knowledge production" (Monahan & Fisher, 2010, p.358) and, as Monahan & Fisher further argue, they can actually be embraced as a benefit of research. They argue that "informants' performances – however staged for or influenced by the observer – often reveal profound truths about social and/or cultural phenomena" (p.358). So, whilst it did not appear that there were observer effects during observations, if any behaviours were being "staged", that data still offered an insight into how both laypeople and professionals conduct themselves during PPI activities. It shows how they wish to be perceived by others when they are conscious of being observed, which offers indications of how they perceive PPI should be conducted.

2.2.2. *Semi-Structured Interviews*

With regards to interviews, a semi-structured approach was taken (Easterby-Smith et al., 2012). Topic guides were initially drafted quite early in the research process to gain

ethical approval (see Appendices 1 and 2). The topic guides covered core generic questions, such as how the person defines their role in terms of PPI and how they came into it; how they view PPI activities they're involved in; what they perceive to be the purpose and outcomes of PPI; and how important they believe it is to them personally and their organisation. These questions addressed the research aims of exploring individual perspectives and conceptualisations of PPI, and exploring role identity interpretations.

More specific questions were asked during the interview, which were developed from observations and information from documents. For example, if an activity observed seemed to cause contentious discussions, it was then pertinent to ask people involved in that activity what they thought the major issues were. The interviews were recorded with a digital recorder to aid transcription. Again, the ethical issues associated with this method will be discussed in section 2.7. A total of 27 interviews were conducted, ranging from 17 to 60 minutes in length; adding up to a total of 16.5 hours of data, with an average length of 36 minutes for each interview.

Formal interviews can have the potential effect of making participants feel obligated to behave and speak in a particular way, like the 'researcher effects' already discussed. However, the confidential nature of the interviews protected them somewhat, potentially alleviating or reducing any anxiety a participant may have had about being open about their practice and views. Furthermore, the interviews were not conducted at the beginning of the research. Observations were conducted for at least three months before the first interviews took place. This was a deliberate intention – the rationale for delaying interviews until after some observations had taken place was to a) allow familiarity and a rapport to build to reduce anxiety for participants, and b) allow context-specific questions to develop to utilise during the interviews. This enabled the interviews to be reminiscent of an informal conversation rather than a formal interview, further alleviating anxiety and reducing potential researcher effects.

2.2.3. *Document Reviews*

A total of 131 documents were collected: 49 from the mental health trust (MHT), 19 from the social enterprise (SE), and 63 documents from the acute hospital foundation trust (AHFT). (Full descriptions of case sites will follow in section 2.5.2.) The reasons for the considerable difference between the quantities of documents collected at each site were partly

the size of the organisations (SE being considerably smaller in size than the other two); and partly due to the number of related activities observed. Most documents were brief in content – agendas, event and activity briefings, and summaries of activities. There were other lengthier documents – minutes of meetings and detailed corporate reports. Much of the content of these documents was not relevant to PPI and, therefore, only partially reviewed. Quality Accounts (a report all NHS providers are required to produce and publish annually) for the two financial years this research took place, and their PPI and quality improvement strategies, were reviewed in more depth. The documents reviewed were either publicly available documents or documents handed out at meetings. Other documents were obtained directly from participants. Confidentiality will be discussed in the section 2.7., though it is worth noting here that any document not already in the public domain was of course treated confidentially.

The main reasons for collecting and reviewing official documents were two-fold. Firstly, to obtain context-specific information on policies, structures, and activities specific to that organisation; and secondly, to aid development of interview topic guides. Many questions during interviews were developed from observations of activities and reviewing official documents from within the organisation. (It should be noted that the Interview Schedules in Appendices 1 and 2 shows only the core questions, and not context-specific questions.)

One issue with collecting documents from an organisation is the potentially biased way in which they may be written. Documents that organisations prepare, particularly those for the public domain, can be written and presented in a way that does not open them up for a great deal of criticism by the public or media. Although these are organisations that are required to be transparent and accountable, they will potentially word topics in the most favourable way possible, focusing on improvements they are making and mitigating circumstances in the case of negative information. Having said this, these issues are not of concern for this study, as the whole purpose of reviewing documents such as policies was to understand how the organisation presents itself when it comes to PPI – what is the ‘official’ purpose; how do they profess to do it in practice; and what are their formal policies and strategies regarding PPI. These issues needed to be understood on balance with the real-time observations and the individual perspectives of professionals and laypeople.

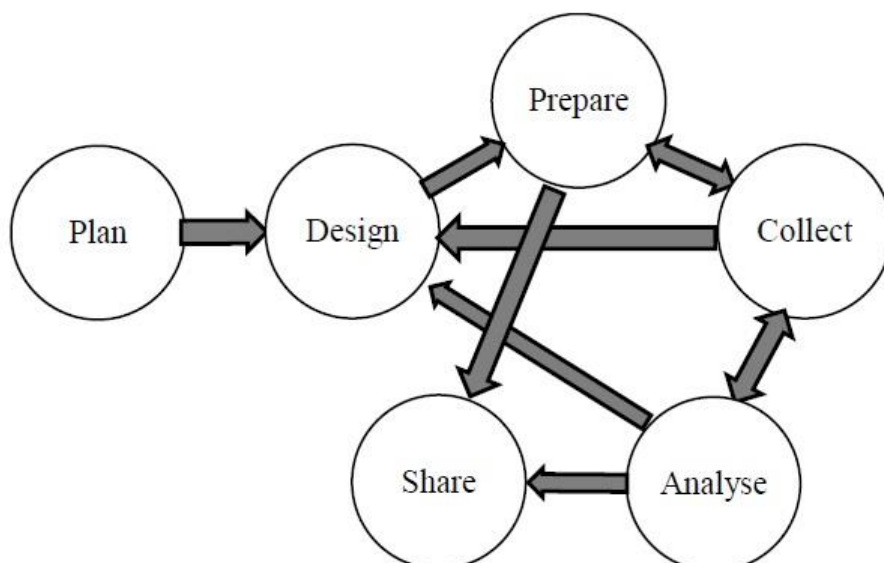
2.3. Methods – data analysis

As already described, an exploratory and interpretative approach was taken. As such, qualitative methods of data collection were employed. Given that the approach was interpretative and evolved throughout the data collection period, the analysis process also had to be interpretative and evolve over time. The analysis went through numerous iterations to develop a comprehensive thematic analysis upon which to base a conceptual framework.

2.3.1. Iterative ‘mapping’ process

The overall approach to analysis was a continuously iterative process, much like Yin’s (2009) description (see Figure 21) of a “linear but iterative process” (p.1). In order to address the research aims, the data analysis had to be a continuous process, rather than a single stage at the end of the fieldwork. As Hammersley & Atkinson (2007) describe, the analysis has been formed through “analytical notes and memoranda...embodied in the ethnographer’s ideas and hunches” (p.158) without a pre-defined formula or process of analysis to follow. It has “involve[d] an iterative process in which ideas are used to make sense of data, and data are used to change our ideas...[with] movement back and forth between ideas and data” (Hammersley & Atkinson, 2007: p.159). Ideas were formed as the data were collected and were not fixed. Through the coding process (which will be described in the next section), ideas were explored, changed, or retracted. This was an on-going process throughout data collection and then throughout data analysis.

Figure 21: Doing Case Study Research: A linear but iterative process (Yin, 2009; p.1)



The data has also been analysed using a ‘cognitive mapping’ approach to develop a conceptual framework of PPI – that is cognitive mapping of ideas formulated from the data, rather than cognitively mapping participants’ ideas. Ackermann et al. (1996) have used cognitive mapping in a range of organisational studies in both the private and public sectors. They suggest researchers may use cognitive mapping for three different tasks: mapping complex and ‘messy’ concepts or problems; defining an interview schedule to facilitate a semi-structured discussion; or managing large amounts of qualitative data from documents. For the present research, the first purpose (mapping complex concepts) was how it was used in practice. By linking together different ideas and concepts, the basis for a comprehensive conceptual framework could be constructed. This allowed one to visualise how different factors interact with one another in order to build a conceptual framework.

2.3.2. *The coding process in practice*

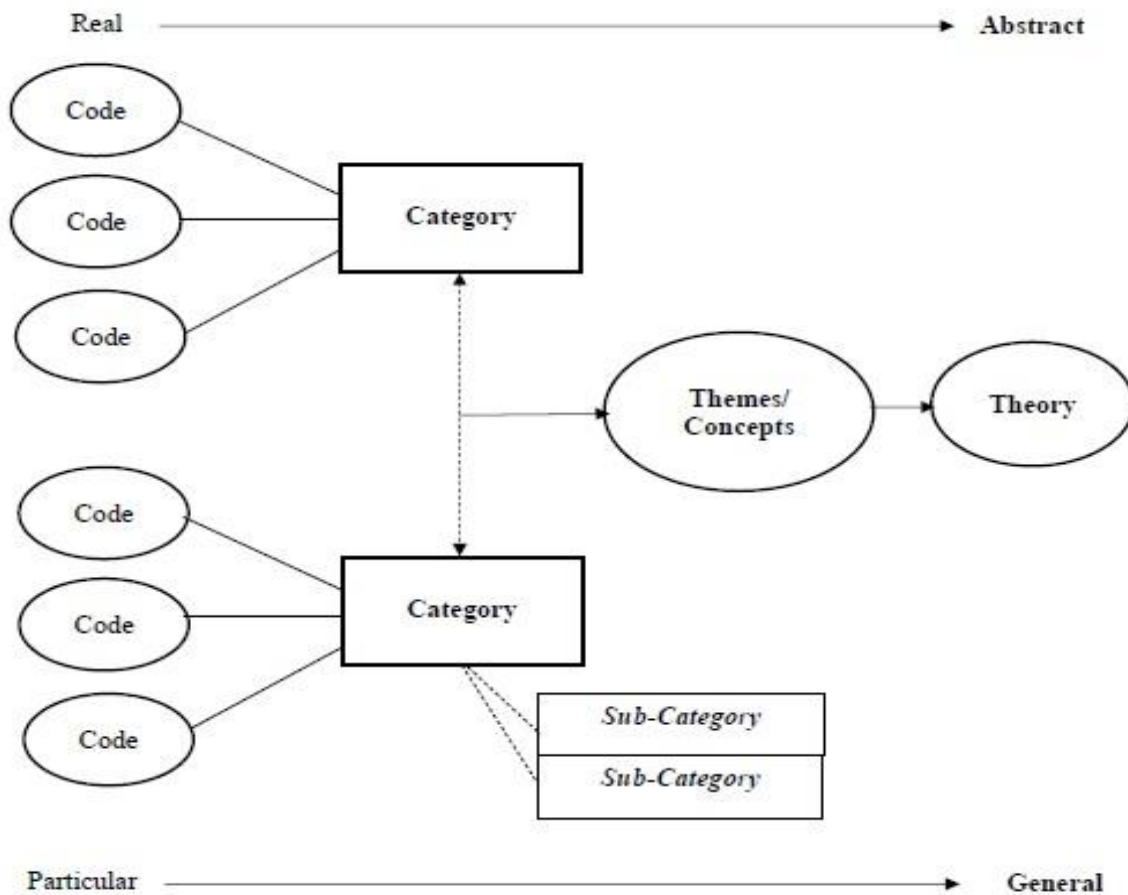
All interview and observation data were coded using QSR NVivo (v.10) Software. The codes used were essentially ‘descriptive codes’, the aim being to apply a label that best articulated the content of that data extract. Through various cycles of coding, a hierarchy of codes was developed: groups of sub-codes within wider codes or categories. The principles of the approach taken on the application of codes can be summarised by a quote from Saldaña (2009):

“qualitative codes are essence-capturing and essential elements of the research story that, when clustered together according to similarity and regularity – a pattern – they actively facilitate the development of categories and thus analysis of their connections.”

Saldaña (2009, p.8)

The numerous iterations of coding and re-coding ultimately led to the development of a conceptual framework that encapsulated the complexities of PPI. Throughout the analysis process, themes derived from the codes were considered in relation to one another in order to theorise about connections between key factors. This process can be summed up by Saldaña’s codes to theory model in Figure 22 below. In practice, there were four main phases, which are described in more detail below.

Figure 22: A streamlined codes-to-theory model for qualitative inquiry (Saldaña, 2009, p.12)



Phase 1 – Code Scoping

From the literature review and an initial read of early data, an initial list of codes was developed. These codes were on one level of analysis – in other words sub-levels and higher levels were not developed at this stage. This was the initial high-level analysis to give a list of initial codes. Code names were attributed to the content of the data across multiple sources. In practice, all interview transcripts and observation notes were read and code labels noted as the data was being read – this led to a very raw set of codes.

Phase 2 – Code application

The codes were then applied to the data and subsequently adjusted to be a more representative label of the content of the data following reflection and discussions with supervisors. They were also grouped into ‘political and societal factors’ ‘individual factors’, ‘organisational factors’, ‘logistical and practical factors’ and ‘outcomes and impact’; therefore, forming two levels of codes. The approach to this phase was what is referred to as “splitting” the data – data extracts were coded with multiple codes (rather than the opposing

“lumping” approach) to highlight the “nuances” in the data at the beginning rather than returning to the data later to further break it down. At this stage, there were numerous occasions when ‘simultaneous coding’ was conducted – the complexities of some of the participants’ accounts required more than one code being applied to each extract (Saldaña, 2009).

Phase 3 – Hierarchical analysis

Following further application of the coding framework to the data, further levels were added (now formed into a hierarchy of three levels). For example, within ‘individual factors’ was the code ‘personal skills’ and within that code were several individual skill examples, such as ‘networking’. This stage of the process went through several iterations as the data was continuously reviewed and reflected on.

Phase 4 – Code labels rationalisation

During the beginning of the write-up phase, code labels were refreshed and/or combined with others. The process of writing up descriptions of themes from the data aided further reflection about code labels. For example, several codes originally placed under “organisational factors” were re-named and/or moved to be encapsulated within “individual factors”, as it was judged that the data suggested individual beliefs about the organisation, rather than a more factually-based set factors, such as reporting structures.

Phase 5 – Conceptual Framework Development

At this stage, a comprehensive coding framework was in place, having gone through several iterations as described above. This enabled the higher-level analysis to begin – linking codes to one another as potential relationships based on observations and the experiences of participants. For example, the type of involvement activity that is employed is based on many influences such as staff skills and knowledge, time constraints, recruitment of participants, competing priorities, financial and physical resources, national policies and guidance, and desired outcomes. Essentially, the codes and their relationships to one another were ‘mapped’, as described previously. This led to the production of a comprehensive conceptual framework.

Throughout the Results sections of the thesis, quotes from interviewees and observation extracts have been used throughout to illustrate each theme. Quotes were chosen based on

their capability to best articulate the theme in question. To ensure there was a breadth of data presented from across the case study sites and participants, the number of quotes from each participant and each case study site was recorded. Table 13 shows the distribution of quotes throughout the analysis.

Table 13: Distribution of quotes throughout results

Theme group	No from MHT	No from SE	No from AHFT	No from professionals	No from laypeople
Political & Societal	5	6	3	12	2
Organisational	22	14	18	45	7
Individual	15	14	13	25	13
Logistical & Practical	3	4	2	8	1
Outcomes & Impact	6	4	4	12	2

2.4. Concerns regarding ‘going native’ and ‘researcher/expert’ role conflicts

One of the concerns at the beginning of the research was the potential to become too immersed in the field. By observing these organisations over a long period of time, there was the potential to ‘go native’ and limiting the ability to have distance enough from the data for analysis. This was largely avoided by allowing sufficient time to reflect on the findings outside of the organisation. Hammersley & Atkinson (2007) refer to this very issue and how to combat it – they suggest sufficient time outside the field should be allowed to process and reflect on the data before moving back in. This is precisely what was done in practice. By moving between three organisations, there was ample time in between observations to continuously reflect on the convergences and divergences in the data, and help to continuously develop lines of inquiry.

Further to this, there was also the issue of potential conflicts between ‘researcher’ role and the ‘expert’ role. The organisations taking part requested reports personal to them with recommendations for improvement, and as such, there was the potential for these organisations to begin to rely on the researcher as an expert. Throughout the data collection period, it was stressed that the main purpose of the research was to develop a conceptual framework which may include some practical issues (i.e. barriers, facilitating factors, roles of individuals, etc.) that may be useful to the organisations. The research was not framed as a collaboration or evaluation work, and it was continuously stressed to the organisations that it was exploratory work only that may not find that any one approach worked over and above another.

Furthermore, to ensure professionalism, as suggested by Easterby-Smith et al. (2012), the terms “research” and “researcher” were consistently used during conversations and interviews with participants. The key leads in each organisation understood this and perceived the primary benefit of my research to be an impartial person’s objective examination of their organisation. (How the leads in each organisation were contacted and each case site recruited will be described in depth in section 2.5.1.) In practice, the reports did provide some recommendations to the organisations; most of which were practical in nature, such as ring-fencing finances. Feedback from all three organisations suggested the reports met their expectations and they have been given the freedom to interpret the findings as they wish.

2.5. Case sites

The following two sections describe how the case sites and participants were recruited, and the details of the final case sites and participants. The overall aim was to be as broadly representative of the UK healthcare industry as possible, and to ensure as many stakeholders within each case site as possible were included in interviews. In all three final case sites, a named PPI lead had been contacted and met with on several occasions to build a rapport and establish an initial understanding of their organisations' PPI mechanisms. Observations and interviews followed on from this in a snowball sampling manner.

2.5.1. Selection process

The aim was to recruit three to four organisations within the Midlands region. It was also decided they should be different types of organisation to allow sufficient representation across the healthcare sector (i.e. acute care, secondary care, mental health care, and community care). It should be noted that no commissioning organisations were contacted, as they were going through major changes as part of the Health and Social Care Act 2012. Although legislation requires commissioners to also consult patients and the public on major decisions, it was felt that the disruption to commissioning organisations at the time would make access to these very difficult. As commissioners were not contacted, this also meant that, by default, primary care providers were also excluded (e.g. GP surgeries), as these services were managed by commissioning organisations. However, these are much smaller organisations and would likely present much fewer data capture opportunities than studying larger organisations. As the research was more concerned with the complexities of PPI in healthcare organisations, studying individual GP practices would likely not have highlighted the wide range of possible barriers and facilitating factors at an organisational level.

Once the initial inclusion criteria had been determined, a 'gatekeeper' was identified at every healthcare provider in one area of the Midlands. Through the local SHA's website, a regional PPI network was identified. The website listed all the PPI leads from the region. Emails were sent to each of these named leads (10 people in total). A further private healthcare provider was also contacted through a contact of one of the academic supervisors. Some did not respond to requests for contact, whilst others replied but felt that they did not have the time and resources to allow a PhD researcher access at that time. Five respondents

expressed interest in taking part, including the contact at the private provider. These contacts were followed up with one-to-one meetings.

The one-to-one meetings allowed for the interested parties to ask further questions about how the research would be done and the aims of the research. Following these meetings, one organisation did not express any further interest in taking part for unknown reasons (an acute trust), and the private provider also later provided no further contact for unknown reasons. This left three organisations who wished to take part. Further meetings with these PPI leads secured access and allowed a rapport to build up, as they would be the key contacts in securing access to activities to observe. Furthermore, two PPI leads agreed to being shadowed for a period of one week to identify initial activities to observe and key contacts to interview. The social enterprise PPI lead did not wish to be shadowed but instead passed on a questionnaire to her contacts across the organisation as a ‘mapping’ exercise of the PPI mechanisms. As this was the smallest organisation, it took less time to identify their key mechanisms and activities, and as such served the same purpose as shadowing the PPI leads in the other case sites.

The final case sites recruited (as described below) were broadly representative of healthcare organisations in that they cover a wide scope of healthcare provision: one mental health trust, one community health provider, and one acute hospital trust. The community health provider was also a social enterprise, covering the third sector provider aspect. The NHS Standard Contract for 2012-13 (DoH, 2011a) describes acute services, mental health and learning disability services, community services, and ambulance services. Therefore, the chosen organisations are broadly representative of statutory healthcare provision.

2.5.2. The final case sites

Below are descriptions of the final three case sites. Information about their demographics has been sourced from Health Profiles (Association for Public Health Observatories (APHO), 2012) (which was the year in which data collection began). Each of the case sites is a uniquely different healthcare provider catering for different healthcare needs. For clarity, all three sites are commissioned to provide NHS services to the public, though only two are NHS organisations.

Case Site A: Mental Health NHS Trust (MHT)

This was a mental health trust serving a total population of around 1 million across a city and large county. The city centre is one of the most deprived in England with a very large black and minority ethnic (BME) community (more than 10%). In contrast, the county is one of the most affluent in England, with a large elderly population. The Trust had an annual budget of around £250 million, employing around 6,000 staff. MHT acquired community health services from the two PCTs in the area as part of the Government's Transforming Community Services (TCS) 2010 programme. As such, since April 2011, the Trust has provided both community health and mental health services.

Priorities for health in the city include tackling health behaviours linked to heart disease, cancer, and respiratory diseases. Health priorities for the county are more concerned with supporting elderly patients and focusing efforts on early intervention and prevention. As for mental health needs of this health economy, there are many young people in the city with significant mental health problems, many related to drug and alcohol misuse. This organisation was also attempting to obtain Foundation Trust status, meaning that during this research, they had gone through the early stages of public membership recruitment and appointment of Governors in shadow form.

Being a large organisation, MHT required a range of personnel, committees, and groups to enable its PPI work. The core team were labelled as the "Patient Experience and Partnerships" team. Within this were a range of key functions: Customer Services (formal complaints, public concerns, and PALS); Patient & Public Engagement (community events, projects, etc.); Equality and Diversity (a function bridged across both this department and Human Resources); and Partnerships (managing partnerships with other organisations, internal volunteers, and social enterprises). The team was small and comprised of two managers (one for Customer Services and one for Partnerships); both of whom reported to a further manager. The Customer Services Manager had four case workers and the Partnerships manager had two support staff. There was then an Equality and Diversity team of four officers who sat across both this department and HR (as their work covered both managing equality and diversity within the community, and equality and diversity within their own workforce). The department also had a Head, whom reported to the Director of Nursing & Quality (Board member).

This department's work fed into a corporate committee called the Patient Safety & Experience Group (PSEG), where other quality reports and projects reported to. As the organisation was so large, each of the four service divisions also had a similar group where key service leads got together to discuss patient experience issues and patient safety within their own division. A representative of the corporate team attended each of the divisional groups to feed back to them about organisation-wide PPI initiatives and relevant policies. The corporate meeting then fed into the Quality Assurance Group, which ultimately fed into the Board meetings. These arrangements were early in their development, as the organisation had only recently taken over both local PCT's community health services.

Case Site B: Social Enterprise (SE) Community Services Provider

This organisation was a social enterprise that was formerly part of the city's PCT, and it employed some 2,000 staff. Before they split from the PCT, they provided community health services to the city (population 300,000). Since they became a social enterprise in April 2011, they have continued to provide such services and have begun partnerships with other voluntary providers and some private providers, demonstrating a move to a more business-like delivery of healthcare services. The city has a diverse population, including a large student population, a range of ethnic minority groups and some severely deprived areas. The city has major problems with heart disease, cancer, and stroke amongst its population, and as such, changing health behaviours is a priority. Another significant health need is related to its young population – sexually transmitted diseases and teenage pregnancies are highly prevalent in the city. With these priorities in mind, health promotion is key.

This organisation was much smaller than the other two organisations, and therefore, had a much smaller department for PPI work. There were just four dedicated roles for PPI: Head of PPI, a Communications & Involvement Officer (whom worked across both the PPI team and the Communications & Marketing team), an Equality & Diversity Officer, and an administrative support role. There was also a separate team to manage formal complaints and provide PALS, reporting to the Head of PPI. The Head of PPI reported to the Director of Nursing & Operations (Board member) and the team was within the Quality Directorate, similarly to MHT. This case site had also recently gone through considerable organisational change having become a social enterprise. The central team ran a Patient Experience Group (PEG) consisting of various senior managers, representatives of charities and other organisations, as well as patients and the public. This group was carried over from the PCT to

the new organisation. A Non-Executive Director chaired PEG. This group reported to the Board via the Director of Nursing & Operations, whom also attended PEG.

Case site C: Acute Hospitals Foundation Trust (AHFT)

This was a large acute hospital foundation trust serving a city and part of a county (around 600,000 people). They had an annual budget of around £450 million. The population they serve has both affluent and deprived areas, including a large BME community in the city. There are around 8,000 staff and in 2004 it was granted Foundation status, meaning less control by the SHA and the requirement to have an elected Board of Governors to call the Trust Board to account. Since April 2011, they acquired some community health services from the local PCT (also as part of TCS), and as such, have been providing these services out in the community since then. The city has similar health priorities to SE, though to a lesser extent. Health promotion and early intervention and prevention are key priorities, and the agenda for moving services out of acute hospitals and into the community more poses significant challenges for this Trust.

Being the largest organisation of the three case sites, they had more resources and personnel dedicated to PPI (though still a small resource, according to interviewees). The roles for PPI, like the other two organisations, did sit across more than one team. Unlike the other two case sites, this organisation did not have a dedicated team at the centre, but instead had multiple functions sitting across multiple teams. Reporting to the Chief Nurse (again within the Quality & Nursing Directorate, similarly to the other two organisations), was a Director of Patient Experience. This post was responsible for various Trust functions: Complaints and PALS, the Bereavement Service, Volunteers, monitoring of patient feedback, and liaising with external organisations (such as HealthWatch). Patient Experience reports were presented at a group called the Patient Experience & Engagement Group (PEEG). This group consisted of staff, Governors, charitable organisations, and patient representatives. This group fed into the Quality Committee, which ultimately fed to the Trust Board.

In terms of staff the Director line-managed, this consisted of the PALS and Complaints teams. Other roles that supported or were involved in PPI work were an Engagement Officer whom worked within the Learning & Development department, and a Communications Officer whom worked within the Communications & Marketing Team. As such, there was no key central team responsible for all PPI work, unlike the two other case sites.

2.6. Participants

Activities relevant to the research were identified through PPI leads in each organisation, and potential interview participants were identified through the observations of these activities. Further activities and interview participants were then identified through these individuals in a snowball sampling manner. A range of stakeholders were involved in both observations and interviews. All those involved had some role in PPI. Most were healthcare professionals and healthcare managers whose role included engaging with patients and/or the public for their employing organisation. Others worked for other agencies, such as Local Involvement Networks (LINKs) (which was in the process of becoming HealthWatch during this research); and voluntary services, whom had a role in engaging with the organisation regarding PPI. Some laypeople were also involved, including patient representatives and advocates, members of the public, existing service users and carers of service users.

Whilst the interviews focused primarily on employees of these organisations, a third of interviews were conducted with laypeople. A full breakdown of participants observed and interviewed is provided in the tables below (Tables 14, 15 and 16). Combining those observed and those interviewed together made a total of 288 participants. The three case sites were evenly represented in interview numbers (9 for MHT, 8 for SE, and 10 for AHFT); a total of 27 interviews (see Table 16 for full breakdown). You may note from the tables the lower number of overall participants in SE. This was for two reasons: firstly, they were a much smaller organisation than either of the two NHS Trusts; secondly, the participants did not want internal governance meetings or activities being observed for confidentiality reasons. This meant that a smaller range of activities were observed for this site, compared to the others, as already indicated in Table 12 in section 2.2.1. This may (or may not) be indicative of the change in the type of organisation (i.e. moving from the NHS to become a private organisation).

The professionals who took part (either observed, interviewed, or both) occupied four different roles: Senior Managers (Head of Department, Assistant Director or Board Member), Senior Clinicians (practising clinicians in roles that have a senior management role, e.g. Divisional Clinical Leads), Front-line Clinicians (practising clinicians whom had a temporary role in PPI for a specific project), Managers (those in management roles at a corporate level),

and Support Staff (those in supportive roles at a corporate level). These groups (except for Senior Clinicians) can be further broken down into Clinical and Non-Clinical (for example, some Managers had a clinical background). Laypeople had four distinctly different roles: Service users, Carers, Professional laypeople (Governors, Non-Executive Directors, and Public Members), and Third Sector (voluntary organisations). Incidentally, most of the laypeople observed and interviewed fell into more than one category. As such they have been categorised based on their primary role in the PPI activity being observed.

Table 14: Observation participants (professionals)

	Numbers of participants (professionals)							
Case Site	Senior Managers		Senior Clinicians	Front-line Clinicians	Managers		Support Staff	Totals
	Clinical	Non-Clinical			Clinical	Non-Clinical		
MHT	9	11	9	17	10	25	18	81
SE	5	2	3	4	1	8	5	28
AHFT	7	8	9	22	3	12	10	71
Totals	21	21	21	43	14	45	33	180

Table 15: Observation participants (laypeople)

Case Site	Numbers of participants (laypeople)				
	Service Users/Patients	Carers	Professional laypeople	Third Sector/Other	Totals
MHT	3	4	8	19	34
SE	11	6	1	12	30
AHFT	12	2	22	8	44
Totals	26	12	31	39	108

Table 16: Interview Participants

Case Site	Numbers of participants (interviews)						Carers	Professional laypeople	Totals
	Senior Managers	Senior Clinicians	Managers	Support Staff	Service Users				
MHT	1	2	3	1		2		9	
SE	3			2	1	1	1	8	
AHFT	2	1	2	1	1	1	2	10	

2.7. Ethics

The following two sections detail some ethical considerations of the research, how these were handled in practice, and how the study was formally approved through both the University of Loughborough and NHS organisations' ethical approval processes.

2.7.1. Ethical considerations

With research involving observing and interviewing individuals, the main ethical considerations are concerned with protecting participants' anonymity. Participants must be fully informed about why the interviews and observations are being conducted and how the information gathered from them will be used. Confidentiality had to be protected at all times. The process of identifying participants, how they would be briefed, how data would be stored and how they would be involved in the research process had to be carefully considered. For this study, having been trained in psychological research, the British Psychological Society (BPS)'s Ethics Committee code of conduct (2009) was followed. The BPS suggests four principles psychologists should adhere to: respect, competence, responsibility, and integrity. As such, the following section is organised under these headings.

Respect

“Psychologists value the dignity and worth of all persons, with sensitivity to the dynamics of perceived authority or influence over clients, and with particular regard to people’s rights including those of privacy and self-determination.”
(p.10)

The research had to ensure it protected participants' rights, such as privacy. All information gathered from each individual had to be securely stored (password protected files on a password protected computer), and anonymised with pseudonyms (on observation notes) and ID numbers (on interview transcripts). Participants were fully informed before interviews and observations took place about why the research was being conducted, and it was stressed to everyone that they had the right to withdraw at any time without having to explain their reasons for withdrawing. All participants signed consent forms (Appendix 3) following reading a Participant Information Sheet (PIS, Appendix 4) on the purpose of the research and the conduct of the interviews, including details of how the data would be recorded.

Competence

“Psychologists value the continuing development and maintenance of high standards of competence in their professional work, and the importance of preserving their ability to function optimally within the recognised limits of their knowledge, skill, training, education, and experience.” (p.15)

As several laypeople and service users were interviewed and observed who, at times, discussed sensitive issues, not only did the researcher have to respect confidentiality, the researcher also had to be alert to potential difficulties. For example, should a service user have expressed anxiety about their condition or tried to seek advice from the researcher, then they would have been advised to speak to their GP or named health professional. Details for contacting PALS were also provided on every PIS. The researcher is not a trained health professional or counsellor, and therefore, any problems the participant wished to address had to be referred to a relevant professional. Furthermore, the researcher did not have the skills to provide support to people with communication or language barriers, and so, again, appropriate professional assistance would have been arranged had the participant not already had anyone to assist (such as a family member). No participants required communication support to be provided.

Responsibility

“Psychologists value their responsibilities to clients, to the general public, and to the profession and science of Psychology, including the avoidance of harm and the prevention of misuse or abuse of their contributions to society.” (p.18)

As this research did not involve any intrusive procedures or interventions, there was little risk of causing harm to participants. However, at times, participants did discuss sensitive and emotive issues. Had anyone shown any signs of distress during an interview, the researcher would have stopped the interview and asked if the participant wished to continue. Again, they would have been referred to a relevant health professional if they needed further assistance beyond the remit of the researcher.

Integrity

“Psychologists value honesty, accuracy, clarity, and fairness in their interactions with all persons, and seek to promote integrity in all facets of their scientific and professional endeavours.” (p.21)

The researcher endeavoured to be as honest as possible about the purpose of the research so that participants were fully informed before agreeing to take part. At no point was any participant deceived or misled, and all participants were given opportunities to ask the researcher further questions and report concerns. Details of the PhD supervisors were also provided on the PIS should participants wish to raise any concerns about the research conduct. All observation notes were written up as clearly as possible, aiming to reflect the events as accurately as possible as they happened.

As a final note, all participants were fully briefed on their rights as above, as well as the general purposes and conduct of the research. All participants were provided with a PIS, as already described, and this enabled informed consent. Written consent was obtained from all participants whom were interviewed. However, it should be noted that, for practical reasons, it was not possible to obtain written consent from all participants whom were observed. Instead, participants were asked to inform the researcher either at the beginning or at the end of the activity if they did not wish to be observed. If anyone had made such a request after an activity had already been observed, the participants would have been presented with two options: either the observation data for that activity would have been destroyed in its entirety, or data would be removed that concerned the individual wishing to be withdrawn. No participants objected to being observed at any time.

2.7.2. Ethical review process

A full ethics application was submitted to the NHS Research Ethics Committee (REC). Loughborough University’s research office reviewed this application first, before being submitted to the REC. A consent form, research briefing, PIS, interview topic guide, and a research protocol were submitted as well. As such, every process of the research conduct has been reviewed and approved formally. Finally, to gain access to each organisation, their Research & Development (R&D) offices were contacted and a full NHS/R&D Permission application was submitted to each. Again, the supporting documents provided to REC also had to be submitted to each R&D office, with minor amendments made to the PIS so that it

was specific to each site (e.g. contact details for their R&D leads and PALS). Following each organisation's governance review of the application, a Research Passport was sought through each organisation's Human Relations department, whom then issued a Letter of Access, allowing access to the organisations for research purposes.

3. Results

The following sections focus on the data collected in five distinct sections: Political & Societal factors, Organisational factors, Individual factors, Logistical & Practical factors, and Outcomes & Impact. These sections are written in a way that is guided by literature on PPI (in terms of the overall structure of the sections) but is essentially driven by the data collected. As such, although the structure is broadly guided by themes identified in the literature, these sections focus on describing and interpreting the data, without explicitly referencing the wider literature. This approach has been taken primarily due to the high volume of data collected (27 interviews totalling 16.5 hours in length plus 51 observations). In describing and interpreting each theme, there will be an interpretative summary that will highlight to what extent the theme adds to or contradicts existing literature, though the Discussion sections will discuss the relevance to wider literature in more detail.

It should be noted that most of the extracts provided are from interview data, with some extracts from observations. This approach has been taken due to the large quantity of qualitative data. Observations led to questions for interviewees, and observations continued alongside interviews. The observations generally informed the interviews but also supported information from interviews as more observations were conducted. As such, throughout the results sections, observation extracts will only be provided where they offer up additional evidence not explicitly or adequately contained within the interview data.

The quotes in these sections also contain further explanation for context, and some contain missing words. These have been shown in [] for the reader's aid. Irrelevant material has been removed, shown by '...'. For example, if the participant was talking about more than one topic, some material has been removed from the extract to limit to only content that reflects the theme being described. All quotes have a unique interview ID, as well as the type of role the individual had and the case site name. All observation extracts also have ID numbers, any names have been replaced with pseudonyms, and other identifiable information, such as place names, have been removed.

3.1. Overview of themes

Before describing the key themes in depth, referencing examples from the data, the following two tables show the initial codes (Table 18) and how they were renamed, combined, and categorised, leading to the final set of codes and theme groups (Table 17). The coding process itself has already been described in section 2.3.2. These tables add to this by illustrating how the code labels developed throughout the analysis process.

Table 17: Final codes and corresponding section numbers of the Results

Level 1	Level 2	Level 3	
1.1. Consumerism	N/A	POLITICAL & SOCIETAL FACTORS	
1.2. Technological age			
1.3. Survey fatigue			
1.4. Reaching marginalised groups			
1.5. Unrepresentativeness			
2.1.1. Board awareness and support	Structural and hierarchy arrangements	ORGANISATIONAL FACTORS	
2.1.2. Limits of capacity of roles			
2.1.3. Front-line staff/service-level engagement			
2.1.4. How PPI roles are defined with organisations			
2.2.1. Culture of mental health vs. traditional medical model	Indicators of organisational culture		
2.2.2. Professionalised language			
2.3.1. Lack of resources	Organisational barriers		
2.3.2. Lack of clear and defined PPI strategy			
2.4.1. Efficiency savings and financial performance	Competing priorities		
2.4.2. Patient safety and risk			
2.4.3. Targets and KPIs - monitoring versus PPI			
2.5.1. Quality improvement	Drivers for PPI		
2.5.2. National policies and initiatives			
2.5.3. Reputation management and transparency			
3.1.1. Patient stories are powerful	Beliefs		INDIVIDUAL FACTORS
3.1.2. Personal stories versus bigger picture			
3.1.3. Personal definition of PPI			
3.2.1. Advocacy	Motivations		

3.2.2. Personal interests and experiences			
3.3.1. Apathy or lack of awareness	Personal barriers		
3.3.2. Fear of involving patients and the public			
3.3.3. Lack of skills			
3.4.1. Communication skills	Personal skills		
3.4.2. Integrity and honesty			
3.4.3. Relationship management			
3.4.4. Networking			
3.4.5. Related previous work experience			
4.1. Methods of involvement	N/A	LOGISTICAL & PRACTICAL FACTORS	
4.2. Logistics			
4.3. Methods of recruitment			
4.4. Targeted and focused projects			
5.1. Impact on individuals - PPI helps develop people	N/A	OUTCOMES & IMPACT	
5.2.1. Changes to patient information			Impact on services
5.2.2. Changes to staff training			
5.2.3. More efficient service			
5.2.4. Increased marketability			

Table 18: Original codes and changes made to codes

POLITICAL & SOCIETAL FACTORS (Level 3)	
Level 1 codes:	
Citizenship	Removed (insufficient data)
Consumerism	No change
Engagement bombardment	Merged with 'Survey fatigue' (data crossover)
Hard to reach groups	Renamed 'Reaching marginalised groups' (more specific)
Lack of power of voices	Removed (insufficient data)
Not speaking out means nothing changes	As above
Lobbying	As above
Market competition	Split out between 'Increased marketability' as an outcome and 'Consumerism' as a societal theme
Media hype	Removed (insufficient data)
NHS reforms confusion	As above
Perception as NHS as one organisation	As above
Survey fatigue	No change
Technological age	As above
Unrepresentative voices	As above
Usual suspects	Merged with 'Unrepresentative voices' (data crossover)
ORGANSATIONAL FACTORS (Level 3)	
Competing priorities (Level 2)	
Level 1 codes:	
Efficiency savings	Renamed 'Efficiency savings and financial performance' (to be less specific)
Patient safety vs. experience	Renamed 'Patient safety and risk' (more specific)
Targets & KPIs	Renamed 'Targets and KPIs – monitoring vs. PPI' (more specific)
Drivers for involvement (Level 2)	
Level 1 codes:	
National policies and initiatives	No change
Political drivers	Combined with above (data crossover)

Reputation	Renamed 'Reputation management and transparency' (more specific)
Review or evaluation highlighted an issue internally	Renamed 'Quality improvement' (more general)
Transparency & accountability	Combined with 'Reputation management and transparency' (data crossover)
Executive-level drive (Level 2) (later combined with 'Structural and hierarchy arrangements')	
Level 1 codes:	
Board awareness	Combined with 'Board support' and renamed 'Board awareness and support' (data crossover)
Board support	See above
External organisations (Level 2) (whole section removed as all sub-codes removed)	
Level 1 codes:	
External bodies' powers	Removed (insufficient data)
Freedom from external powers	As above
Partnerships with other organisations	As above
Relationships with other organisations	As above
Structural & Hierarchy arrangements (Level 2)	
Level 1 codes:	
Feedback to the front line	Combined with 'Staff engagement' and renamed 'Front-line staff/service level engagement' (data crossover)
Historical set-up	Removed (insufficient data)
How roles are defined by organisation	No change
Poorly defined or fractured structures	Removed (insufficient data)
Raised awareness at front line	Combined with 'Staff engagement' and renamed 'Front-line staff/service level engagement' (data crossover)
Service-level ownership	As above
Staff engagement	No change
Skilling up front-line staff	Combined with 'Staff engagement' and renamed 'Front-line staff/service level engagement' (data crossover)
Top-down vs. bottom-up management	As above
Infrastructure (Level 2)	

Level 1 codes: Data capabilities & IT infrastructure Governance structures	Removed (insufficient data) As above
Organisational culture (Level 2) (renamed ‘Indicators of organisational culture’ (more specific))	
Level 1 codes: Culture of continuous improvement Culture of mental health enables PPI Good internal relationships Professionalised language Progress is slow Reactive rather than proactive Traditional medical model & paternalism	Removed (insufficient data) Merged with ‘Traditional medical model & paternalism’ and renamed ‘Culture of mental health vs. traditional medical model’ (data crossover) Removed (insufficient data) No change Removed (insufficient data) As above Merged with ‘Culture of mental health enables PPI’ and renamed ‘Culture of mental health vs. traditional medical model’ (data crossover)
Methods (Level 2) (renamed Logistical & Practical Factors (Level 3))	
Level 1 codes: Adapting methods for different groups Agenda setting Importance of a range of methods Imposed methods (e.g. national surveys) Involvement of service users in decision making Logistics Meaningfulness Targeted projects Timing for involvement (what stage in process)	‘Merged with ‘Importance of a range of methods’ (more general) Removed (insufficient data) Renamed ‘Methods of involvement’ (more general) Merged with ‘National policies and initiatives’ within ‘Drivers for PPI’ (data crossover) Removed (insufficient data) No change Removed (insufficient data) Renamed ‘Targeted and focused projects’ and split out with new them ‘Reaching marginalised groups’ within ‘Political & Societal factors’ Removed (insufficient data)
Organisational barriers (Level 2)	
Level 1 codes: Bureaucracy	Removed (insufficient data)

Difficulty measuring impact	As above
Lack of communication out to community	As above
Lack of resources	No change
Nature of patient group or services	Merged with 'Culture of mental health vs. traditional medical model' (data crossover)
Reorganisation and structure changes	Removed (insufficient data)
Tokenistic efforts to involve	As above
Organisational view of PPI (Level 2) (removed – all codes in this group moved elsewhere or removed)	
Level 1 codes:	
Defined strategy (or need for it)	Renamed 'Lack of clear and defined strategy' (more specific) and moved to 'Organisational barriers'
Patient experience vs. involvement	Merged with 'Targets and KPIs – monitoring vs. PPI' (data crossover)
Ambiguity of terms	Removed (insufficient data)
Personal stories vs. bigger picture	Moved to 'Beliefs' (data suggested it was more of an individual belief than organisation-wide theme)
INDIVIDUAL FACTORS (Level 3)	
Beliefs (Level 2)	
Level 1 codes:	
Involvement delays change	Merged with 'Involvement anxiety' (data crossover)
Power of stories	Removed (insufficient data)
PPI helps develop people	Renamed to 'Impact on individuals' (more general) and moved to 'Outcomes & Impact' (data suggested it was more of an outcome than only a belief)
Improves self-esteem	Merged with above
Staff experience relates to patient experience	Removed (insufficient data)
View of service users as partners	As above
Motivations (Level 2)	
Level 1 codes:	
Advocacy	No change
Personal definition of PPI	Moved to 'Beliefs' (data suggested it was more about a personal belief/definition rather than motivation)

Personal interests and experiences	No change
Personal barriers (Level 2)	
Level 1 codes: Apathy Lack of awareness of importance across staff Fear of exposure Limits of power of role Time constraints Want to involve but ill-equipped or supported	Merged with 'Apathy' (data crossover) Renamed 'Fear of involving patients and the public' (more general) Renamed 'Limits of capacity of role' (data suggested it was not about individual power, but rather about the limit of role tasks) and moved to 'Structure & hierarchy arrangements' Removed (insufficient data) Renamed 'Lack of skills' (more specific)
Personal skills (Level 2)	
Level 1 codes: Being clear on purpose Being outspoken Diplomacy Integrity & honesty Maintaining relationships Managing a large group Networking Related previous work experience	Merged with 'Integrity & honesty' (data crossover) Remove (insufficient data) Renamed 'Communication skills' (more general) No change As above Removed (insufficient data) No change As above
Outcomes & impact (Level 3)	
Level 1 codes: Better communicated change Changes to patient information Changes to roles Changes to training and staff development Co-delivery of services Innovation (or potential for it)	Removed (insufficient data) No change Remove (insufficient data) No change Removed (insufficient data) As above

Increased marketability	No change
More efficient service	As above
New service added	Removed (insufficient data)
Review or evaluation of service	As above

3.2. Political and societal factors

This section describes the political and societal influencing factors identified in the data. The professionals interviewed (and indeed some of the laypeople) described several societal and political influences on PPI processes and outcomes. These factors included consumerism (the changing way in which service users or patients access services and their increased expectations); the technological age (the changing way in which patients and the public communicate with services, e.g. through social media); survey fatigue (patients and the public being overwhelmed by providers seeking their views); the marginalisation of certain minority groups of society; and the concept of ‘unrepresentativeness’ of the patient and public voice.

The changing societal backdrop for healthcare service provision has, from what professionals interviewed claimed, driven and influenced how and why organisations consult and communicate with their patients and the public. As such, you will note from later descriptions about Organisational Factors (such as methods of PPI) that political and societal factors have a key influence over organisations and, therefore, the individuals who work within them. The changing environment within which healthcare now operates was discussed at length in sections 1.1.1-5. in terms of increased demand and expectations, and increased pressure for transparency and accountability. As such, much of the data presented in this section supports findings within the literature.

3.2.1. Consumerism

Several professionals described the wider societal landscape as a backdrop for the changing attitudes and behaviours of patients and the public in relation to healthcare. They described many factors that are potential indicators of consumerism (consumerism here meaning increased choice and competition between providers) as factors that contribute to the higher expectations of patients and the public, both in terms of accessing services and in terms of having their say. The professionals interviewed recognised the impact this has on how patients and the public behave – they want instant access to services, they want freedom of choice, and they want to be able to voice their views freely.

Professionals and laypeople alike acknowledged this can all have an impact on PPI activities – in all three sites there were reports that there has been an increase in PPI activities

and feedback from patients. The two quotes below from professionals show how aware professionals were about the changing attitude and behaviours of patients and the public. Although healthcare is a public service paid for by the taxpayer, the suggestion was that it is being treated more like a consumable service. These suggestions support existing literature that discusses the changing landscape of healthcare (see section 1.1.1-5).

“...the thing is, even our big supermarkets and big multi-national chains...They want people to complain to say, “I had a rubbish experience” because that’s how they can know how to improve their services. And I think that’s what we need to be doing as a public-sector organisation, to go “Right, tell us the bad bits because we want to make it better for everyone”.”

SE: Support Staff (IB007)

“Society has changed; the public’s expectation is they want everything instantly now, because that’s how it is outside, so part for me is we’re very good at assuming what they want, but we’re not very good at telling them what it is we want [referring to stopping people coming to A&E unnecessarily].”

AHFT: Senior Manager (clinical) (IC008)

3.2.2. *Technological age*

Linked strongly to consumerism is the technological age we now live in. The use of social media means people can communicate with one another immediately and can, therefore, express their views on a range of topics instantly, including the use of public services. The professionals interviewed suggested their organisations needed to be more open to the world of social media and other immediate forms of communication (e.g. SMS texting), acknowledging that this is how many people prefer to communicate, as demonstrated in the quotes below. This suggested they were concerned that, if they didn’t communicate in these ways, they may potentially be missing, or even excluding, the voice of some patients and the public.

The immediacy by which people can communicate with public sector organisations also means that organisations must be ready to respond quickly, as these conversations are in the public domain, unlike patient surveys and formal complaints. When patients and the public make negative comments about a service, if that service does not respond at all, or responds

in an inadequate manner, the public will see this and this can potentially negatively affect their reputation. In the literature, there have been few references to the impact of the rise of social media (see section 1.2.3.). The data presented here indicates that the use of social and digital media as methods of patient and public involvement may likely increase. This has implications for how organisations communicate with their patients in terms of the frequency and quality – contacts will likely be more frequent, but of less depth than other methods of communication. This will be returned to in section 4.2.2 of the Discussion.

“...they [young people] may want to do something, you know, in a different way. So, using technology, so if we had...a Facebook site, or if there was something more interactive on the website; ways in which they could actually feedback on, or maybe even sort of texting them. We could text it to them, so click whatever for ‘yes’ and something for ‘no’.”

SE: Non-Executive Director (IB008)

“And we’re also looking at text messaging, because we’re struggling for them [staff] to get the [survey] cards filled in and returned. And we’re also looking to have something on the web so the patient has got an opportunity in various ways...They are quite effective and I think, you know, in the emergency department it’s the walking wounded; most of them have a telephone, and it’s not just for the smart phones; [a survey] can go through a landline as well.”

AHFT: Senior Clinician (IC006)

Some laypeople interviewed also talked about how technology is contributing to more consumerist attitudes towards healthcare. They made the same acknowledgement professionals did that organisations do need to accept these new methods of communication, as demonstrated in the quote below. This suggests that these individuals may have the perception that NHS organisations have not been responsive enough to the public’s changing preferences of communication.

“I think that they [SE] will have to carry on involving as many patients and other members of the public as possible to improve...because communication is changing; because we’ve all got this stuff [points to laptop]; because of social

media, because people are constantly, 24/7, communicating with everything. It's changing the landscape whether we like it or not."

SE: Carer Representative (IB004)

3.2.3. *Survey fatigue*

As use of the NHS increases, logically, so too does the demand for patient feedback. However, professionals interviewed described how the public can become tired of being asked to give their views, since they experience it with many other services they access (both in the private and public sectors). Professionals described how they needed to be wary of not demanding too much from patients and the public, as shown in the quotes below.

In addition, they were also aware that other NHS providers would be going through the same issues and that they could all be trying to consult with the same populations of patients, asking them the same questions. It is possible that, if the public feel overwhelmed with requests for feedback and involvement, they may begin to disengage with organisations. This presents a considerable challenge for PPI facilitators in that they must strike a balance of seeking meaningful involvement and feedback, whilst not over-burdening the public.

"The other barrier, like I said, was this bombardment, like overkill involvement, because all the Trusts were being encouraged to consult and engage and to get [public] members...and the public just see it as [one], they don't understand that the NHS is lots of organisations, like a franchise, isn't it?"

MHT: Manager (non-clinical) (IA002)

"I've sort of noticed at the supermarket, you get the "are you happy with this? Fill in our survey". Every time you buy something online, something pops up saying "Were you happy with how we addressed your query?" And I think people just get a bit, well, it just adds time to your day; [the public are] fed up with it."

MHT: Manager (non-clinical) (IA008)

"We have really good interface with them, we're asking [patients for feedback] all the time. [But] I think we need to be careful that we don't get survey fatigue. Because patients may have been asked the same one question lots of times. So, we might be saying "how do we deliver services in the right place for you?" And then

commissioners might be saying “where do you want those services?” So, I think we’ve got to be careful and mindful of not bombarding people with things.”

SE: Senior Manager (non-clinical) (IB006)

3.2.4. Reaching marginalised groups

Many professionals interviewed were aware of the need to ensure they involved and consulted marginalised groups of society – the disabled; BME and non-English speaking communities; and lesbian, gay, bisexual and transgender (LGBT) groups. They showed acknowledgement that these groups will inevitably have specific needs and wishes when it comes to healthcare and that they possibly needed to do (or already had done) more targeted PPI work with these individuals.

The below quotes demonstrate professionals’ wishes to engage with these communities, and in some instances, there were success stories (e.g. SE had designed a remote service specifically for travelling communities). This suggests that professionals (but PPI facilitators in particular) had strong moral reasons for wanting to engage with minority groups. The need to engage with minority groups also potentially influences what methods of PPI are utilised. Furthermore, the data presented here does not support claims in the wider literature about the potential deliberate marginalisation of minority groups in society (see section 1.2.).

“I think the difficulty will be reaching the hard to reach communities, whether it is people with learning disabilities or [a] particular section of society who don’t engage well with the Trust...so there will always be groups of carers and patients whose voices are not usually heard. I think it’s about reaching them and bringing them on board.”

MHT: Senior Clinician (IA005)

“The other big group we’ve engaged with is the travellers...we’ve met with the traveller elders who are representatives for the travellers...They were really honest with us, when travellers turn up [at healthcare services] no one wants to know...so in terms of those long-term conditions, we’ve done some really innovative remote working with them, so Skyping so that they can be seen [by a clinician] wherever they are.”

SE: Senior Manager (non-clinical) (IB006)

3.2.5. Unrepresentativeness

A problem facing all three organisations (and therefore categorised as a societal issue rather than an organisational one) was the issue of the ‘representativeness’ of the people they involved in PPI activities. For all three organisations, the core group of people who tended to be involved in committees and projects were retired white people from a professional background (former healthcare workers, teachers, councillors, etc.). This has been identified at length in the wider literature (see sections 1.2.1-2). The professionals interviewed (and some laypeople) described how a lot of their PPI activities involved ‘the usual suspects’, as illustrated in the quotes below.

“So, when I look round and think “I can’t see any young people”, I see faces that have been around for a long time... Well how does that reflect on the organisation if we haven’t moved on far enough? This is me being really honest.”

SE: Senior Manager (clinical) (IB005)

“Some of the other types of barriers we have are to do with the types of people that we engage with. Certain groups in the community are more willing to engage with us than others so it’s difficult to engage with, you know, probably a young person who’s got a family and a busy career...you’re more likely to get engagement from those that are retired and have got time on their hands.”

AHFT: Manager (clinical) (IC006)

The reasons why the same core group of individuals continued to work with the organisation were seemingly complex and ranged from how the organisation attempted to recruit participants (see section 3.4.3.) to motivations for individuals getting involved (see section 3.3.2) to ‘networking’ behaviours by individuals (see section 3.3.4.4.). Although these factors will be returned to in later sections, the quote below goes some way to illustrating how complex it is to obtain a ‘representative’ voice.

“There’s also something about the way that we do it means that you only genuinely hear one voice anyway...so we do awareness and involvement events and you’ll get people to come along, and depending where and when it is, those that would come along anyway because of their civic civil type thing. And they’re the people who go to the council meetings, they go along to committees, they like to know what’s

going on because of their civic duties...we get too much into this idea of focus groups and talking to people, and then the people who turn up aren't the real [target group] people!"

MHT: Senior Manager (non-clinical) (IA006)

Some laypeople interviewed also identified representativeness as a potential problem in the activities they were involved in. Interestingly, they also made some suggestions (though not explicitly) that they themselves were not representative and see themselves as professionals – note from the quote below how the individual refers to himself and others as ‘colleagues’, which is a very professional term. These perspectives support large amounts of research that has shown professionals question the representativeness of the participants (see sections 1.2.1-2).

“The only danger is that it’s getting to the stage where it’s the usual suspects, if you like. So, its people like myself and my colleagues who seem to be involved in nearly everything, and we don’t often see outsiders, if I can use that term. It’s a shame because it would be nice to keep getting fresh blood coming along.”

MHT: Carer Representative (IA007)

3.3. Organisational factors

This section details participants' descriptions of organisational factors that, in their view, influence, inhibit, or facilitate PPI in their organisation. This section covers factors such as organisational structures (worker roles, reporting lines and governance arrangements), policies and strategies (both PPI-specific but also wider influencing policies and strategies), resources (financial, staff numbers and capacity), and external influences (such as national policies/guidelines). As a case study approach was taken to look in depth at three organisations, you will note that, unsurprisingly, this section is the largest and broadest part of the results. PPI processes and the influencing organisational factors were present across the organisation and not localised to any one area of the organisation, hence the level of detail here.

Much of the previous research into PPI, as described already in the Literature Review sections, has focused more closely on individuals and interactions between stakeholders, and processes. This research has been different in that, whilst it did observe individual behaviours and explore individual perspectives of PPI, the data collection was done at an organisational level (i.e. PPI across the organisation rather than individual processes). As such, overall, many of the factors described in this section either do not support prior findings or offer new or nuanced findings. The data also offered an insight into the subtle differences between various healthcare providers – something which, again, has not been appreciated extensively in the wider literature on PPI. As such, organisational factors will feature considerably in the Discussion sections.

3.3.1. Structural and hierarchy arrangements

This section describes organisational structures within which PPI processes were placed, and how they either facilitated or inhibited successful PPI. Professionals described various structures, such as key teams within the organisation, reporting lines up to the Board, and governance committees and groups. PPI fed through the whole organisation in all three case study sites but to varying degrees, as you will note from some of the quotes. In section 2.5.2., each case study's structures were outlined in detail to demonstrate how different the three case sites were in terms of how PPI processes feed up, down and across the organisation. The PPI facilitators interviewed provided descriptions of which structures did or did not facilitate PPI, which follow in the next sections.

Interestingly, one of the laypeople interviewed provided her detailed perspective (quote below) of organisational hierarchies, comparing the NHS to other “rigid” hierarchies such as the military. Her suggestion appeared to be that PPI can get lost in hierarchies when the pressures from above become more about reporting performance numbers than actively listening to and engaging with patients and the public. This helpfully sets the tone of this section.

“Because hierarchies, which the health service is a classic example...the hierarchy is so rigid, and not enough people look at it like that. When you’re in it [as a worker], it’s embroiling isn’t it? ...I mean Stafford [Francis, 2013] and stuff like that doesn’t surprise me in the slightest, because that’s what you get when you get a rigid hierarchy. You know, if someone’s standing on your head and there’s several people above them standing on their heads, then the outcome is [poor care as seen at Mid Staffordshire NHS Foundation Trust].”

SE: Service User Representative (IB004)

3.3.1.1. Board awareness and support

Many of the professionals interviewed initially stated that the Board members supported them with their PPI work but alluded to a somewhat limited understanding and awareness of the complexities of PPI. They suggested that Board members did not fully appreciate the power and potential of PPI in supporting the strategic direction of the organisation. There was some suggestion by PPI facilitators that the Board was more interested in assurance that they were providing satisfactory care rather than actively involving patients and the public in developing services.

“Sometimes I feel that they [the Board] don’t always quite understand what’s actually involved in it...I hear them talk about the patient experience programme, they’ll get the name wrong and you’ll think “Ah, you don’t really understand.””

MHT: Support Staff (IA009)

“I get a really good sense from people like the Chief Executive that this is actually really something that she is passionate about. I think it feeds all the way up to the Board...Whether or not they appreciate what this can do for them, I’m

not sure. I think it is absolutely desired, [but] maybe just from that assurance perspective.”

AHFT: Senior Manager (non-clinical) (IC002)

It is important to note here that it was not completely clear why PPI facilitators held these views of their Board members. Many PPI facilitators had little direct involvement and interaction with Board members (due to reporting lines positioning them at least two levels below Board), so it is difficult to understand the roots of their perceptions. They could be reflecting their own personal views based on a handful of short direct interactions with Board members, or they could be basing their views on the hearsay of other colleagues.

Interestingly, however, professionals from SE made no such suggestion about Board members, and seemed to feel their Board were fully behind PPI (as you will note from the quote below). This may be indicative of the subtle differences between NHS organisations and independent providers. In later sections, you will note there are other indications that SE was quite different in that it was, reportedly, a freer organisation. It was relatively free from Government scrutiny and performance management compared with the two NHS Trusts. It was also freer in how it spent its budget given that the organisation made a profit that could then be reinvested in services as they saw fit.

“That was good because that was the first time our Chair [of the Board] came to the Patient Experience Group just to talk about the importance of the patient voice to the organisation. He was quite adamant that it’s critical to the organisation...[and] the feedback that I got from our members afterward was that they felt there was that genuine importance.”

SE: Senior Manager (non-clinical) (IB002)

In terms of practical and tangible support from Board members, the professionals interviewed described examples such as defined strategies and policies being in place, clear reporting streams, and physical links to Board members, such as having them attend key groups. Again, there was an apparent difference between the NHS organisations and SE in that these more tangible examples of Board-level support were more prominent in SE. In SE, for example, their main patient involvement forum was chaired by a Non-Executive Director, and the Director of Nursing attended the group’s meetings to take feedback directly to Board.

The reasons for these differences are not completely clear – for one thing, the professionals interviewed were not necessarily aware that they were different in any way to other healthcare providers, so they couldn't articulate possible reasons. One might theorise that, as SE was less pressured by governing bodies and national targets than the other two case sites, their Board members may have been more able to offer tangible support because their attentions were not being drawn elsewhere. Board members in the two NHS Trusts were potentially more concerned with assurance metrics than PPI work because of larger pressures to meet Government targets. The competing priorities in these organisations will be described in more depth later in section 3.2.4.

“I mean the [PPI] strategy was done. The strategy's development, actually, was headed up by the Chief Nurse; it was a passion of hers that she wanted to get [in place].”

MHT: Manager (non-clinical) (IA002)

“Well having a Non-Exec chairing the meeting and having our Director of Quality, Safety and Nursing attending every meeting, I think that proves that there is a lot of importance from their side.”

SE: Support staff (IB001)

3.3.1.2. Limits of capacity of individual roles

This refers to the perceived limitations of the role the individual had, particularly the roles of PPI facilitators. Although these descriptions may arguably be indicative of the perceptions of individuals and not organisational structures, the professionals referenced hierarchies and reporting lines. As such, this theme has been placed within Organisational Factors. PPI facilitators referred to their lack of capacity or power in making decisions and enacting changes that were required as outcomes of PPI work. The primary reason cited for this was that they were based in centralised roles and did not directly manage individual services. Their sense of a lack of power did not appear to stem from their own personal limitations, but instead from an acknowledgement of the boundaries of their role within their organisation. This is illustrated in the quotes below.

“I think the other thing is, as well, [the Board] think it's in safe hands so they think not to worry about it because...nothing's ever backfired on us, nothing's

gone wrong, we've never had a complaint that we've not done [PPI]...My worry is that one day we won't save the day because we won't know [service change is] happening [at service-level] ...It's very difficult at the minute because we are so massive now...[Before] I knew people, I got to hear what was going on a lot more. I was able to just go "Oh, have you thought about doing some involvement on this, like a focus group?", and I was able to say, "Well I can help you with that". We're so massive now I don't get to hear what's going on as much, and I can't save the day because I haven't got the capacity."

MHT: Manager (non-clinical) (IA002)

"[However] there was mixed effectiveness in that engagement, because sometimes I'd hear great ideas...but my ability to actually deliver those, because I was an engagement officer, you're the middle man...you don't have the power to make the change."

AHFT: Support Staff (IC003)

One might argue that PPI facilitators may be externalising their sense of a lack of power and capacity, rather than admit it may be something personal to them. Interestingly, one of the individuals quoted above had attempted to resolve the limitations his role had by taking it upon himself to set up a small working group. The group included key individuals from across the organisation in various roles – communications and marketing, public membership, and public engagement. However, as described in the quote below, his attempt at a solution had, in his view, failed. Again, this was cited to an external reason. He claimed that, due to a lack of established organisational structure, there was nothing to “tag that [work] into”, and the individuals in the group lacked power in their poorly defined roles. In other words, the group’s work had no clear reporting line upwards and, therefore, had no power to enact change.

"The engagement group is something that I established because the PEG [Patient Experience Group] wasn't working for the needs that I had. My problem that I had about my role...was there was no engagement structure to tag that into... ..there was no engagement strategy, there was no engagement policy or procedures, there was no structure to feed into...That void meant that I ended up having to take that lead to support the outcomes that I'd set myself because, otherwise, it would have been very silo pieces of work with communities with no

power to deliver...So, I established that group...[sighs] [But] it just really got involved with politics, who had the power to make those decisions? And so, this core group kind of limped along, trying to think what its remit is, what are its powers?" [The group disbanded altogether a few months after this interview took place.]

AHFT: Support Staff (IC003)

A rather unique perspective on this came from a layperson who had previously worked in that organisation in a senior position. She explained that moving out of the organisation into an external lay role as a Governor had given her more freedom to speak out, as she reported previously feeling that she had to align herself with the wider organisation's policies and procedures. She seemed to be suggesting she now had greater freedom and could "influence in a different way" than when she was an employee of the organisation.

"And also influence in a different way [than when I was a senior nurse] because when you work within the Trust, to some degree, towing the party line, you know; you can't necessarily always put your own views, so [being a Governor is] a good way to do that."

AHFT: Governor (IC001)

A recurring theme that will be discussed in depth in the Discussion sections is the notion that PPI facilitators have a considerably important role – a person responsible for facilitating patients and the public having a voice. As such, they are required to communicate well with patients and the public, and must get engagement from front line clinicians and managers to make service improvements. They become a negotiator between patients and the public, and health professionals and managers. The complexities of this role understandably come with many challenges, which will be discussed in more depth in section 4.9.

3.3.1.3. Front line staff/service-level engagement

This theme refers to engagement of front line staff in PPI processes. As all the professionals interviewed were not front-line clinicians, they expressed how important they felt it was to get front line staff engagement, both in PPI work and making service improvements based on PPI work. Some of the descriptions of successful PPI already discussed have alluded to the importance of making productive connections between patients

and the public and front-line staff (one of the main roles of PPI facilitators). The professionals interviewed shared a view that, at a very basic level of PPI, not enough patient feedback is shared with staff and, therefore, they do not feel engaged or involved in PPI (or sometimes even aware of PPI altogether).

They also expressed the view that sharing more feedback from patients with staff (both positive and negative) would engage them better and make PPI more effective. Most interviewees described what appeared to be genuine desires to share feedback with staff for transparency, and to involve them in key change processes and development of services, as demonstrated in the quotes below. The first quote below goes further than this and describes an example of successful staff engagement.

“Our patient experience programme is something that’s been recognised nationally as something that’s special and quite different...the more that we do this, the more staff are seeing the value of it...staff are coming out and saying, “That was just the best thing I’ve ever done...I never get the time to just sit and listen to patients.” ...I think they’re really seeing the true value of it, and the impact of it.”

MHT: Manager (non-clinical) (IA002)

“I don’t think we give staff enough feedback from the patients; I don’t think that’s consistent...have you seen in [some] services they actually have them [patient comments] on the notice boards? ...Because that’s what each team should have - “here’s how we’re doing, here’s how we’re performing, here’s what patients are saying” ...seeing that as part of their job to actually engage and involve [them]; some of those dialogues; it being routine.”

SE: Senior Manager (clinical) (IB005)

However, one quote from a Senior Clinician in AHFT suggested sharing patient feedback with staff was a way of calling them to account and determining what staff developments or training were needed. This person even suggested that most changes needed as a result of patient feedback required “staff training” to improve services, suggesting a perception that most negative feedback from patients was down to poor staff behaviours. Whilst “celebrating” good feedback is noted in the quote below; the individual’s emphasis is

on performance management and changing staff behaviours. This might suggest that sharing patient feedback with staff sometimes serves performance management objectives rather than staff engagement objectives. This concept will be discussed more in section 4.12.3., as this has implications for further research.

“And the idea is that we’ll celebrate what’s good but then they’ve got to explain to us what was not so good and...what their actions are going to be. So, what we’d like to be able to do [is] to see where we need to focus first on the training for staff...because it will be the things patients have raised most times that we’re not so good at. But it’s also about celebrating what we are good at.”

AHFT: Senior Manager (clinical) (IC008)

Furthermore, there were some suggestions that PPI initiatives are more successful (or potentially so) if front line services have ownership of them. In other words, the purpose of involving patients and the public, and the changes or service developments needed as a result of PPI, needed to come from the staff themselves, and not just be imposed on them by corporate managers. The theory seemed to be that if front-line staff felt they were in control and had autonomy in these matters, they would be more empowered to fully engage in PPI and make service improvements. This will be discussed in more depth in section 4.3.1.

“And you know, we feel, I think as a corporate [team]; we feel we own it more. If there was any way of getting them and the divisions, clinical staff, to own it just that little bit more, that might help [its success].”

MHT: Support Staff (IA009)

“There were a few [staff]...that actually came to us to say, “I’d really like to know more about patients coming through and how we can help improve, because we’ve noticed this real problem.” Children’s, for example, had done some previous pieces of engagement...what they ended up doing was work with young people to design a space, which they did.”

AHFT: Support Staff (IC003)

Some laypeople also talked about the value of front line staff being directly involved in PPI initiatives (as shown in the quote below), and they particularly seemed to value having direct contact with front line staff themselves.

“I think the best bits are when they get people in who actually do the job or manage the people who do the job, to come in and say, “This is what we’re doing, what do you think?” or “How does it affect you personally?” I think that’s the sort of communication; it’s got to be grass roots communication really.”

SE: Service User Representative (IB004)

From observations of front-line staff being involved in PPI activities, it appeared to enable greater discussion of various issues, as they could answer questions from patients and laypeople in more detail than PPI facilitators could. This is demonstrated in the observation extract below, where a nurse answered a query from a cancer patient about why consultants prioritise asking them about specific side effects of chemotherapy.

“Brian then asked the nurses if some side effects are more important for medical staff to know about than others because he’d been repeatedly asked about pins and needles...Lisa responded that they want to know all side effects but things like pins and needles could suggest neurological damage that they need to pick up early and other side effects might indicate infection, which can sometimes be life-threatening.”

AHFT: Focus group with chemotherapy patients (OB019)

Furthermore, there appeared to be a wider debate within these organisations about who should ultimately have responsibility for PPI. Both PPI facilitators in the NHS Trusts described how they wanted to strike the right balance between bottom-up service-level ownership for service developments and top-down dedicated management and coordination of PPI. They argued that too much service-level ownership potentially leads to duplication of efforts and a lack of organisational strategy, whereas having solely central responsibility for PPI and service developments allows front staff to deny responsibility. In both scenarios, there is also potential for conflict between front line staff and central corporate managers. The concept of defining roles around PPI will be described further in the next section.

“What do we need to do going forward? And part of that is I need to look at should there be a dedicated resource within [service] divisions? ...I’m not saying you should have one completely as somebody’s job, because actually I think there’s a value in not having a post.”

MHT: Senior Manager (non-clinical) (IA006)

“I could see there could come a time, like there was in my last organisation, where my role doesn’t necessarily need to exist. Because by naming something, to name a lead on something, often, therefore, people don’t feel it’s their responsibility. They kind of devolve themselves of responsibility...And actually, what I’m trying to do is say “It’s everyone’s job, no matter where you are in the organisation.””

AHFT: Senior Manager (non-clinical) (IC002)

3.3.1.4. How PPI roles are defined within organisations

Following on from the previous theme, this theme refers to the definitions placed on roles in terms of work tasks and purposes, which were wide-ranging for both core PPI facilitators and peripheral PPI workers. Participants talked mostly about how their roles and tasks had been designed around organisational goals and drivers (see three quotes below). This differs from descriptions by participants about how they identified themselves in terms of motivations and purpose, which will be discussed in section 3.3.2. As such, this theme has been categorised in Organisational Factors, rather than Individual Factors.

There were several participants who had taken on PPI as part of their role because they were already doing some PPI work in another role. Others had their role specifically put in place for PPI, especially when there was a specific organisational goal to meet, such as increasing public membership. How a person’s role had been defined for them seemed to have implications for how successful they could be in terms of achieving the set goals. As already described, PPI facilitators reported having big challenges in terms of capacity where PPI was part of a wide-ranging role. We have also already noted a key challenge in terms of the limits, or boundaries, of their roles as well, given that they are primarily a facilitating role with little decision-making power.

“[My] role came about...when there was a problem with partnerships in the organisation, a lot of complaints, so I was asked to have a look at that...looked at partnerships, looked at the voluntary sector, statutory partnerships, and then somehow ended up with patient experience and patient partnerships as part of that.”

MHT: Senior Manager (non-clinical) (IA006)

“The organisation decided that it had a Head of Communications and a Head of Involvement and...that they needed an officer to work underneath both roles as a joint role...what they [the Board] saw was that communications and patient and public involvement overlap in a lot of ways.”

SE: Support Staff (IB001)

“I think now, with the Director of Patient Experience leaving the Trust, the Director of Nursing approached me a few weeks ago and said that her and the Chief Exec had discussed the post and wanted me to look at whether I could encapsulate the two items [Facilities Management and Patient Experience], as there’s a lot of cross-over. I said “yes”. I’m now regretting it!” [jesting tone]

AHFT: Senior Manager (non-clinical) (IC007)

3.3.2. Indicators of organisational culture

The following sections refer to participants’ ideas about how the ethos of their organisation either facilitated or inhibited PPI and change/service improvements needed following PPI activities. Much of the data presented here comes from participants themselves but is also supported by observations. Culture here refers to common behaviours in the organisation and the language commonly used in each organisation (both as described by participants and witnessed during observations). This is in line with Pratchett & Wingfield’s definition of ‘public service ethos’ (as cited in Needham, 2006) that “ethos is not a description of individual behaviour, but a set of norms creating a ‘logic of appropriateness’ for those working in public services” (p.846).

An example of language differences between organisations can be illustrated through how they described their client base. Firstly, MHT representatives rarely used the term ‘patients’. They instead tended to use the phrase ‘service user’ (their PPI strategy was also

titled ‘Service User and Carer Involvement Strategy’). This may reflect that the organisation and the people within the organisation did not wish to view their client base as ‘patients’ (which is a passive term), and instead wished to refer to them as service users; it being a much more neutral term (see section 1.3.3. for descriptions of differing terms in literature).

Staff in AHFT, on the other hand, mainly referred to ‘patients’, and not ‘service users’. This reflects a more paternalistic relationship, where the focus is on ‘fixing’ patients (the medical model). This has potential to conflict with the ideals of PPI. The only instance where anyone in this organisation used the term ‘service user’ was the Head of Midwifery during a meeting. She made the case that women accessing maternity services in hospital are not ‘patients’ as they are (mostly) perfectly healthy and are instead being assisted in a natural bodily process. This potentially demonstrates that maternity services had a different relationship with their client base than the rest of the organisation – perhaps more of a partnership than a traditional clinician-patient relationship. Interestingly, they also had a long history of PPI, whereas other areas of the organisation were reportedly either not engaged in PPI at all, or were only just beginning to see it as a valuable activity.

SE employees tended to use terms more interchangeably than the other organisations, but did often use the term ‘patients’. This was frequently the preferred term used by clinical staff that perhaps had a history of a more traditional relationship (i.e. clinician and passive patient) with their service users. The term ‘service user’ or ‘consumer’ tended to be used by those in management or support staff positions whom had no clinical background.

These subtle differences in the language used by professionals in these three different organisations may demonstrate differing underlying views about their client base, and differing organisational cultures. The terms a person uses to refer to or describe another person can be useful indicators about how they view them and their relationship with them. As already described, the term ‘patient’ is a more passive term, suggesting an underlying assumption they are in a subordinate position to professionals, whereas ‘service user’ suggests a more consumerist view of the relationship. These differences will be discussed in more depth in section 4.3.4.

3.3.2.1. Culture of mental health versus traditional medical model

As already mentioned, MHT representatives had a different approach to how they talked about their patients (in that they didn't refer to them as 'patients'). Their language and behaviours seemed to suggest they were more at ease and experienced in PPI activities. As described in the quotes below, it was possibly something inherent to mental health professionals who, by the very nature of their work, need to actively listen to and involve their service users to treat them successfully. Treating mental health conditions is heavily reliant on effective communication between clinicians and their service users, therefore, potentially making staff in mental health organisations more at ease with PPI.

“but you would expect a mental health clinician to be very good at listening to service users and carers by the very nature of their work.”

MHT: Manager (non-clinical) (IA003)

“I think actually mental health services are traditionally very good at finding out what their service users want...So I think it is a high priority in this organisation.”

MHT: Manager (non-clinical) (IA008)

This contrasts with the other two case sites, which primarily treated physical ailments and injuries. Health professionals treating physical problems do not necessarily always need to rely on communicating with and involving the patient to successfully treat them (for example if someone comes to hospital with a broken leg). In the case of acute care, sometimes communication is physically not possible at all, such as in cases where the patient is unconscious. The point here is that mental health problems can *only* be identified and treated through communication with, and involvement of, the service user. As such, mental health providers may likely have a different relationship with their client base compared with other health services, particularly acute hospitals.

This all indicates a very different culture operating within mental health compared with other healthcare providers; one that may lend itself more easily to PPI ideals around partnership and engagement. Interestingly, one of the PPI facilitators in AHFT recognised that individuals working in acute trusts are not necessarily as understanding of the principles of PPI as mental health professionals (as shown in the quote below).

“I was talking to...people from...the mental health trust. And, oh my god, I was just so jealous that they get it, particularly in mental health...They realise that the only way to change behaviour and improve health is through an engagement model, investing in it.”

AHFT: Support Staff (IC003)

The traditional relationship between healthcare professionals and patients is paternalistic, as already discussed at length in the Literature Review sections. Even the word ‘patient’ implies they should behave passively. As such, both PPI facilitators and laypeople interviewed in AHFT claimed that engaging front line staff (particularly medics) in PPI activities was very difficult, as it challenged the paternalistic relationship.

“I have to say, although the manager and the rest of the staff are very proactive, getting the doctors involved is like pulling teeth really. You can reluctantly get one of them at a meeting occasionally, to stay at a whole meeting, but the overall impression is they tolerate us [Governors] because they’ve got to have us [there]. [Participant laughs.]”

AHFT: Governor (IC001)

“We struggle even from a medical model about the whole “the patient is the expert” principle. That is something that we really struggle with here...my impression is that most senior people would say “what on earth would they [patients and the public] know about improving how we can deliver services?””

AHFT: Support Staff (IC003)

3.3.2.2. Professionalised language

A commonly reported barrier for successful PPI (as described by both professionals and laypeople) was communication problems because of professionalised language (or ‘jargon’). Observations showed that many medical and technical terms were used, and there was frequent use of acronyms by professionals, making it very difficult for laypeople to actively contribute to all conversations. Some of the literature suggests the use of professionalised language serves as a tool by which professionals can maintain power (see sections 1.3.3-4 and section 1.4.4).

However, observations (example observation extracts below) also showed that PPI facilitators used jargon less frequently than those not in PPI roles. PPI facilitators also tended to aid communication by requesting that the professionals using jargon explain or clarify what they were saying. This further demonstrates the important role that PPI facilitators have in facilitating communication between professionals, and patients and the public. As PPI facilitators have frequent interactions with laypeople, it may be that they are simply more experienced at using lay language when compared with other professionals, whom more regularly use medical language in their health profession roles. Therefore, rather than professionalised language being used as an attempt to maintain power, it may simply be a more frequently used way of speaking that is difficult to draw back from, rather like a person's mother tongue.

“Alison kept talking in acronyms and had to be called up on it several times by the Chair – by the end they were joking about the health service’s preoccupation with acronyms.”

SE: Presentation from ambulance representatives at a Patient Experience Group (OB007)

“There was a discussion going on between Michael and Gerald about the meetings and Gerald’s reports to the other Governors and the Trust Secretary...Gerald advised he had been unsure exactly how to report about these meetings, particularly as he found a lot of information very technical and difficult to understand. Jane asked if Gerald would benefit from pre- or post-meeting briefings to help him make sense of the content. Gerald said he would like a briefing both before and after these meetings.”

MHT: Beginning of governance meeting that included a lay member (OA008)

The professionals interviewed were reportedly very aware of these issues, and their descriptions seemed to suggest there was no active attempt to exclude laypeople from conversations by using jargon. It was instead described as a genuine mistake a lot of professionals make, and that people simply “forget” (IC003) to adapt their language, as illustrated in the quotes below.

“I mean one of the key challenges when you bring groups of professionals...and service users together [is] jargon; using language that everybody can relate to and understand. We are all aware that in the NHS, like a lot of other public-sector departments, we forget we speak in a language that isn’t easily understandable to people who aren’t from within the organisation. A lot of acronyms...So that’s been one of the key challenges really.”

MHT: Manager (non-clinical) (IA003)

“I think there’s obvious barriers; so, for some people it may be to do with complexities of some of the information; it’s very bureaucratic, there’s lots of kind of acronyms and jargon, you know. Anybody who’s not used to that coming into health, it’s quite a daunting arena to come into. So, I think that kind of informational barrier, and understanding, might be a barrier for some people.”

Case Site B: Non-Executive Director (IB008)

However, others argued that sometimes it is necessary to simply exclude laypeople from technical conversations due a perceived lack of understanding. As illustrated in the quote below, if a layperson is involved in something very technical and actively contributes to the conversation, it may suggest that they are another professional rather than a layperson, as described in the two quotes below.

“And we’ve had the discussion at a couple of the sub-committees of the Board...at one point we were saying you should have public involvement in all aspects of the Trust, which sounds brilliant, of course we should; until you start saying “the finance and procurement committee”; hugely technical. And unless you get someone there as a member of the public who’s a chartered accountant, they’re not going to understand it. And if you’ve got someone who’s a chartered accountant, have you got public involvement or have you just got another professional at the table?”

MHT: Senior Manager (non-clinical) (IA006)

“I can definitely see patients going on, like, the Equality & Diversity committee. [But] I think it might be too early in terms of the complexity. I think we’ve, sort of, talked about other committees. I mean governance, they go through things that

are so complex, do we really want [them there]? I mean it's not that a patient can't take part, but we might need like a specialist patient who knows about that kind of stuff."

SE: Non-Executive Director (IB008)

Laypeople described how the use of professional language and jargon made them feel. The common feeling was one of confusion, and sometimes even stronger feelings of exclusion. Interestingly, however, the laypeople rationalised why this happens and did not seem to feel professionals actively attempt to exclude them, as demonstrated in the quotes below. One layperson said she felt "out of her depth" (IA004) at times, but also that there will be matters they cannot take part in, because of their technical nature. Another layperson suggested professionals use jargon out of habit more than anything, like the professionals themselves suggested.

"Well they're very friendly, but I do sometimes feel out of my depth. Well I'm bound to; I don't understand everything... dashboards and [name of IT system], and they've got to have that, but that's far from the patient side, and I don't know anything about the IT side of things...there's bound to be things that we aren't privy to."

MHT: Carer Representative (IA004)

"But I can understand sometimes when you work in offices it's a military thing. Everything's got to be [snaps his fingers] snap [rationalising use of jargon]. [But] it doesn't help carers, and it certainly doesn't help service users, when they use that chat...if they bring it to a meeting and they want you to be involved but they talk like that, it's like walking into a room and suddenly everyone starts speaking French. And then you feel alienated."

SE: Carer Representative (IB003)

3.3.3. Organisational barriers

This section describes some of the barriers perceived to be at an organisational level: specifically, a lack of resources (financial and physical), and a lack of defined organisational strategy. Many other organisational barriers were also identified, such as bureaucracy, reorganisation and organisational change, and inter-departmental relationships. However,

there was insufficient data to discuss these matters in depth here. The majority of data drawn upon for these themes is from interview data. As such, it is important to note that these are the perceptions of individuals about their organisations. Having said this, several participants made the same claims across all three sites, suggesting these were considerable issues for those involved in PPI work.

3.3.3.1. Lack of resources

In these times of austerity, it was not surprising that the professionals interviewed described having problems because of a lack of resources; be it financial, physical or staff (or all three). As none of these organisations had a specific budget for PPI, the activities they conducted were immediately limited in terms of how participants would be covered for expenses, what materials they could use (such as marketing materials at events), what venue/s could be used, and even what time of day it could be conducted (if, for example, they needed to pay staff overtime for holding activities outside of office hours). One professional even used the phrase “beg, borrow and steal” (IA009) to express the difficulty they had in fully resourcing PPI activities.

“I don’t think they have the resourcing that’s needed to do it properly. And partly, I guess, it’s something for me to think about is how do I get that message up without sounding like I’m moaning [laughing], because everyone could say they’re not resourced enough. I kind of need a bit of a business plan for why we need a bit more resource.”

MHT: Manager (non-clinical) (IA002)

“Capacity, you know, we’ve basically got [the Head of PPI], and half of [the communications and PPI officer]’s role. And I think of lot of his role is taken up with the communications and marketing side. So, we don’t have enough capacity...we have to look at what we’d like to do, and then look at the resource implications and say “are we willing to put the resources in to meet that?” And it might be that we actually have to scale down what we want to do.”

SE: Non-Executive Director (IB008)

“Once the plans [for engagement events] have been agreed, it needs to be resourced, and that can sometimes be a challenge. I run membership on a bit of a

shoe string really. When I have the members talks, I'll go to Aldi and get biscuits! ...anything that's not spent on doctors and nurses, they [the public] tend to think it's a waste of money."

AHFT: Manager (non-clinical) (IC009)

Professionals, particularly those in core PPI roles, expressed that they felt senior management (e.g. Board members) would ultimately need to decide how valuable they felt PPI was and provide a sufficient budget in response. This suggests that they possibly felt PPI was not valued enough within their organisation. It is perhaps also indicative that PPI is not a high priority in these organisations, despite reports from professionals that Board members had expressed support. In the literature, (see section 1.5.3.) there are some whom have raised the issue of the costs of PPI and the potential for costs to outweigh the benefits. Unfortunately, it was not possible to access data in the case sites about costs, financial or otherwise, and there was no suggestion from any of the interviewees that costs outweigh benefits. This does not necessarily indicate that the benefits are greater than the costs, but instead might merely demonstrate the cost is not something these individuals are concerned about. Given that all participants interviewed raised the issue of a lack of resources, it demonstrates that they likely perceive the benefits to outweigh the costs.

3.3.3.2. Lack of clear and defined PPI strategy

The professionals interviewed described how important it was for their organisation to have a defined strategy. AHFT was the only site that did not have a specific PPI strategy, whereas the other two organisations did. This was reflected in the professionals' interviews – those from the two organisations that had PPI strategies felt relatively well supported in their role and partly attributed this to the fact the organisation had a strategy. They also described having a sense of purpose and direction, as shown in the quote below.

"I would say at the moment yes [I am supported] because there is the strategy and there is drive within [the organisation]. I think for me service user involvement is really on the agenda... Whereas I think historically, I think it was a nice idea but actually it wasn't a priority."

MHT: Senior Clinician (IA001)

However, in AHFT, most professionals interviewed made at least some reference to the lack of strategy and direction at an organisational level when it came to PPI. They described feeling they had no clear purpose and were working in isolation because of the lack of organisational strategy. This suggests that having a strategy in place was important to the PPI facilitators' sense of purpose and in giving them a feeling of support.

“Oh, and the other thing was we never had a strategy [rolling eyes]. I don't think I've ever seen a strategy on patient experience. Various ones were made...[but] at very senior levels [people] have very different opinions about what its purpose was so it never got signed off. So, all the years I was here, it never got signed off and there wasn't one before that from what I hear. So, there was no direction on what's our purpose, what's the outcome, what do we really want to get out of engagement?”

AHFT: Support Staff (IC003)

“this Trust itself has to set that strategy at the top to say what is the Trust engagement priorities...hopefully, [it] will be driven by the clinical divisions up the organisation and back down again, so there shouldn't be any reason why [it wouldn't work], if the engagement strategy has been set by the Board.”

AHFT: Manager (non-clinical) (IA008)

3.3.4. *Competing priorities*

A considerable organisational factor professionals reported was competing priorities and balancing efforts and resources between differing priorities. All three organisations involved were complex and relatively large, presenting significant organisational challenges. Furthermore, as all three organisations serve the taxpaying public, they are accountable on multiple counts – delivering high quality care, demonstrating they offer value for money, and offering transparency to the populations they serve. Any activities these organisations conduct that do not clearly and directly support these priorities can, understandably, be put to the bottom of the priority list. The following themes fall under the overall theme of 'competing priorities' in that these were the sorts of reasons why professionals claimed PPI activities (or service change needed following PPI activity) were pushed lower down the priority list.

3.3.4.1. *Efficiency savings and financial performance*

A major challenge for all three organisations (and all public-sector organisations during the time this research was conducted) was to continuously save money under rising pressures at a societal level to reduce public spending. This has, unsurprisingly, had a considerable impact on how these organisations operated and determined their spending decisions. There were two key points made by professionals who were interviewed. At times, they either had to make a service change because of a pressing financial reason and were, therefore, limited in what they could involve patients and the public in; or the wishes of patients and the public couldn't be acted on because of financial pressures elsewhere. This is illustrated in the quotes below.

“This might be my controversial thing that I might want to retract! [said whilst laughing and looking at the recorder] But if service managers have got to make changes pretty damn quickly because there isn't any money coming in, and if by consulting service users and listening to what our service users' expectations are, those things don't match, then we're not going to be consulting with our service users are we? If you cannot deliver what service users are asking, what is the point of asking them?”

MHT: Senior Manager (clinical) (IA001)

“And the financial situation. I'll come to it last, but the financial situation is always on our lips. And it would be very easy as an NHS manager to say, “Well I haven't had enough money”. I think I have had enough money. [But] I'm fed up of having to give transformational CIP [Cost Improvement Plans] parts. Actually, it makes my job harder.”

AHFT: Senior Manager (non-clinical) (IC007)

In one interview, however, a PPI facilitator expressed quite a different perspective. She suggested that, even if service changes are driven by financial pressures, service users can still be involved. In her view, the benefit of involving service users, even when there is perceived to be little they can influence, is that they may have a suggestion that professionals haven't necessarily considered. Their suggestions, she expressed to believe, may result in efficiency savings (see section 3.5.2.3. for more on this). The below quote from this individual illustrates this point.

“I think the best one we’ve done so far was on a really emotive subject and that was the psycho-oncology service, which is where we were proposing some changes to psycho-oncology [including the removal of one senior specialist for financial reasons]. It was quite emotive and lots of angry patients...Actually, the views of the patients completely changed what they were planning to do. They still got the same outcome that they were looking for [saving money] but they did it in a way that still met the patient needs.” [Instead of making the specialist redundant, a new skill-mix was introduced to save money without patients losing a key health worker.]

MHT: Manager (non-clinical) (IA002)

Some carer and patient representatives were also aware that involvement and consultation with people like themselves doesn’t always happen, especially when there are financial drivers behind a service change. In the example below, a carer representative describes a consultation activity where, essentially, a decision had already been made and was perceived to be motivated purely by financial reasons.

“The consultation was between the transport department and the people that run the day centre. Not the people that use the day centres...the person it affects [i.e. the service user] doesn’t even get involved...So a half-hearted 3 weeks discussion or consultation. Sorry, it’s not a consultation. It’s a joke isn’t it? And all because they wanted to save some money.”

SE: Carer Representative (IB003)

3.3.4.2. Patient safety and risk

Some professionals talked about the need to govern patient safety and risk issues being so important that it sometimes overshadowed the efforts to promote patient experience and conduct PPI activities. The Lord Darzi Next Stage Review (Secretary of State for Health, 2008) proposed that all NHS organisations needed to govern themselves against three domains: Clinical Effectiveness (how effective they are at treating patients); Patient Safety (reducing the risk of harm); and Patient Experience (patients’ satisfaction levels).

Although Lord Darzi’s recommendation was for the three domains to be seen as equal indicators of quality, it seems in reality organisations may have placed greater emphasis on

some over others. The professionals interviewed described how they (and/or their colleagues) were often pulled to more pressing priorities relating specifically to Patient Safety (see quotes below). Patient Experience governance and improvement was even described by one participant as a “nice idea” (IA001) activity rather than the perceived essential task of Patient Safety governance.

There may be multiple reasons for placing more emphasis on one domain over another. Firstly, it may simply be that the organisation has more established governance arrangements for Clinical Quality and Patient Safety and, therefore, workers were given more work directly linked to these domains over and above Patient Experience. Another possible explanation may be that Patient Experience is less easily measured – there are tangible metrics to measure Clinical Quality and Patient Safety (e.g. mortality rates and number of falls, respectively). This may then lead to an emphasis on measurable quality indicators over and above Patient Experience and PPI work. Unfortunately, as there were no clear descriptions from professionals as to where the pressures were driven from (e.g. Board members), it is only possible to theorise where these pressures may originate.

“We tried to merge the two [governance] groups, because Patient Safety and Patient Experience, there’s a lot of crossovers...But what we realised was the patient safety agenda is quite heavy. Patient experience got marginalised a lot, so we didn’t really do justice to patient experience.”

MHT: Senior Manager (non-clinical) (IA006)

“But the priority’s got to be to keep people safe. It does. Absolutely. I say everything else is rescinded almost. Safety is paramount...[Patient] experience is there as well, as kind of the next one down. But safety’s got to be of paramount importance. So whenever you’re stretched, that’s what you will focus on.”

AHFT: Senior Manager (non-clinical) (IC002)

3.3.4.3. Targets and KPIs – monitoring versus PPI

As with being pressured to make efficiency savings and being pulled to focus on Patient Safety, the need to monitor against targets and KPIs was noted by professionals as particularly challenging. Professionals described having to produce lengthy reports and acknowledged that this took much of their time away from more developmental work.

Essentially, they were distinguishing between *monitoring* patient experience and *improving* patient experience – the two responsibilities require different work tasks and, therefore, differing levels of resource and effort, as demonstrated in the quote below.

PPI tasks generally fell into the latter category – developmental work that had the general aim of improving a service by involving patients and the public in developing or redesigning it. But given that these organisations were under great scrutiny (particularly in the wake of the Mid-Staffordshire scandal, Francis, 2013), it is not surprising that the monitoring role of these professionals generally took precedent. Furthermore, participants described many of the targets and KPIs as being related to, or directly influenced by, Government initiatives and targets. As such, the drivers for focusing on these issues were apparently not solely driven by internal sources, such as priorities at Board level.

“Part of my role is to bring those two things together...rather than just constantly looking at the transactional, which is complaints, complaints, complaints. It’s important for intelligence, but, to keep doing that on a daily basis, is exceptionally time-consuming and as a result I’m not allowed; well not “allowed”, that’s the wrong word. But time constraints mean that it’s difficult to sit down and do that [transformation] piece of work, [the Board] think, “well it can wait”.”

AHFT: Senior Manager (non-clinical) (IC002)

Notes from observations supported how challenging it was to be tasked with monitoring and meeting so many targets whilst simultaneously being expected to put time and effort into improvements and developmental work. This meant that, more often than not, some of the developmental work PPI facilitators intended to do either did not happen at all or started but did not complete. Observations of key governance meetings (see extracts below) demonstrated that much of the discussion was around the numbers of complaints and incidents, with only some mention of developmental work underway. (It should be noted that, as no governance meetings could be observed at SE, evidence for this theme from SE is sourced from interviews only.)

“Catherine then said she feels that both complaints and compliments reporting are too “numbers-driven” and doesn’t provide this group with anything

meaningful to discuss and produce actions against. Catherine said they need a standard approach across MHT as well so they can compare themes with the other Divisions and come to some common strategic agreements.”

MHT: Discussion about monitoring complaints at governance meeting (OA001)

“John then asked the group to think about what else needs to be in the [Engagement] strategy. Andrew suggested they need something on outcomes – what do they want to get out of it and how can they measure it. Andrew referred to outcomes such as lower stress, and reduced complaints. Julie stressed it shouldn’t turn into yet another monitoring exercise though, and that maybe they don’t need to measure it at all because ad-hoc stories are just as powerful as numbers sometimes.”

AHFT: Discussion about new strategy at Patient Experience & Engagement Group (OC001)

3.3.5. Drivers for PPI

There was an array of drivers for PPI cited by professionals, as illustrated in the first quote below. Professionals framed drivers in terms of the specific purposes of PPI activities, but also in general ideological terms around improving the quality of services. From their organisation’s point of view (as described by these individuals), most PPI activities were primarily about making improvements to services – they would involve patients and the public in helping them to shape how a service might be re-designed or developed. This seems a logical and pragmatic perspective on PPI, and is likely what most people would expect PPI is for, but there were other drivers too, as you will note from the following sub-sections.

“They’ve had a notion which has been driven by, kind of, you know feelings, feedback from staff, or whether it’s been a financial one or whether it’s been through a complaint, or it’s been a mixture of those things, they knew they needed to do something, and so, you know, they held events that were informed by service users and they have made a change as a result.”

MHT: Senior Clinician (IA001)

3.3.5.1. *Quality improvement*

As already mentioned, a general need to continuously improve services was reported as a primary driver, or at least the general ethos behind PPI. The quotes below illustrate this point. Ultimately, as providers of healthcare services, the quality of care provided is of the utmost importance. This was the most commonly cited purpose for PPI work, which supports findings of previous research (see section 1.3.2). As one PPI facilitator put it, PPI can serve as a “tool [for improving] patient experience” (IA002).

“I kind of see it as a tool for helping us with our patient experience agenda. So ultimately, my role is to make services better and fit for purpose, and my belief is that you can only do that by involving and listening to patients about their experience. And about how that experience might give them ideas on how we might make things [better], how we might do things differently.”

MHT: Manager (non-clinical) (IA002)

“I think quality of care to the public is the most important thing...And if I’m honest, a lot of my focus is on that bit...And that if we were to engage beautifully with all of the public, all our patients, and we had all the strategies in place, but actually we didn’t have really fab services at that delivery of contact, then what would be the point? That absolutely is the driver, the quality. Are we giving the best possible service that we can?”

SE: Senior Manager (clinical) (IB005)

What is interesting in these accounts of the purposes and drivers of PPI, little is mentioned of precisely how PPI can meet the intended goals. For example, the first quote states that improving services is reliant on involving and listening to patients, but it does not go into any detail about how this is done. This suggests that the purposes and intended outcomes of PPI can be rather vague, and this in turn has the potential to reduce the impact of PPI work. In a later section (3.3.4.2.), the skill of being honest and upfront with participants about what they can realistically influence was cited as important for PPI facilitators. However, if the purpose of the activity is not clearly defined in the beginning, it will be difficult to be honest and clear with participants.

3.3.5.2. National policies and initiatives

Certain drivers for PPI could easily be used to explain why PPI activities can be ‘tokenistic’, and national policies as drivers is one such example. At times, healthcare organisations are expected to implement new guidance or make changes to services based on national policies and priorities. A national body (such as DoH) instructs them to make changes to a service, or review the provision of services for a specific user group. Certain tasks and roles (such as recruiting public members) are driven solely by meeting these requirements. As such, tasks that meet these requirements could be described as ‘tick-box’ exercises.

“When you’re a Foundation Trust...You have membership, which is drawn from the members of the public...And the idea is that those members have a bit of a vested interest in those services that we provide and are able to, if we have any developments, we share with them to get their views on what we provide and what we should be spending our money on. And as I say, the members elect the Governors and the Governors are their sort of mouthpiece.”

MHT: Manager (non-clinical) (IA008)

“There is a Government initiative which is called the Equality Delivery System, and within that system is requirements to engage with diverse patients. So, there’s two angles: one that we had noticed our own gap from hearing from different service users; and also from pressures to meet this standard we’d signed up to.”

AHFT: Support staff (IC003)

At times, being driven by a national initiative or policy did mean that involvement of patients and the public was, frustratingly for some, very limited. This is illustrated in the quote below. It is indicative of an industry that is heavily driven by Government policies, which is potentially a detriment to other valuable work.

“So, we’ll go out and involve people...but actually, we were going through some national initiative, we can’t change it, you know, we’ve involved people on something that it really, really doesn’t matter what they say. We’re bound by it because it’s a national initiative, so there’s that up-front thing about saying to

people “Happy to hear your voice, but it’s a national thing, if you don’t agree with it, speak to the Government.”.”

MHT: Senior Manager (non-clinical) (IA006)

3.3.5.3. Reputation management and transparency

Transparency and accountability has been a key theme throughout this research. By inviting patients and the public to get involved in key service developments, organisations are meeting requirements to be transparent, but it appeared the purpose of PPI extended beyond the general need to be transparent. Another key driver for involving patients and the public was reportedly to manage the organisation’s reputation. Sometimes not involving patients and the public had the potential for damaging the reputation of the organisation, so PPI facilitators recognised that the organisation needed to involve people to prevent bad press. Note in the second quote below, the interviewee uses the term “ambassadors” to describe Governors, and another PPI facilitator described how patients can become “allies” (IA002) for the organisation, defending their reputation.

“I think people need to always think if a decision’s [been] made, voluntary and patient groups are very, very vocal; they’re very strong and powerful. If one voluntary organisation has had a bad experience of [name of SE], it spreads like wildfire. So, things like that, we have to be very careful.”

SE: Support staff (IB001)

“[Governors are] more like ambassadors as well because I think these times where the press is very quick to criticise the NHS, we need people out there to say “Well, actually I’m a Governor at the hospital”. And you don’t expect them to give the very detailed operational response, but they can generally say to them “I’m a Governor at the hospital and, in my experience, this is what I’ve been told.””

AHFT: Manager (non-clinical) (IC009)

As already discussed, the need for transparency and accountability has driven healthcare organisations to quite literally open their doors to the public (e.g. through inspections, appointing Governors, etc.). PPI facilitators, other professionals and laypeople recognised that a key driver for PPI was the need to be transparent and accountable, as shown

in the quotes below. There were also some specific references to the Mid-Staffordshire Inquiry (Francis, 2013) being pivotal in losing the public's trust and, therefore, transparency and accountability was the only way to regain that trust. As such, the driver appears to be more than just being transparent, but also about maintaining their reputation.

“It’s at the core of the organisation to be interactive with patients, to be keeping them informed every step of the way, being transparent and to really show them we care about what they’re giving us and appreciate their views because we can have all the best ideas in the world, but is it practical? Is it good for patients?”

SE: Support Staff (IB001)

“And I think for [the Marketing Manager] to come from the commercial world, it’s like “So the Director puts themselves in front of the patients not knowing what the questions are going to be?” and it’s like “Yeah, but if you’ve got nothing to hide, then you’re just happy to do it.” ...So, it’s about that transparency and being honest.”

SE: Senior Manager (non-clinical) (IB006)

3.4. Individual factors

This section describes professionals and laypersons' views on what individual characteristics either aided or obstructed them and their peers. A distinction between organisational and individual factors is made here in that organisational factors were largely perceived to be beyond the control of individuals; whereas individual factors were internal characteristics participants attributed to themselves or others. For example, participants would talk about their own beliefs but also the beliefs they perceived others to have. In both cases, they were arguing they are personal to that individual rather than being about the organisation as a whole.

3.4.1. Beliefs

This first section is about the beliefs held by both professionals and laypeople interviewed. Participants expressed beliefs that service user experiences and views are just as important as staff experiences and views, and that service users and professionals should always work in partnership. But there was also an acknowledgment that these beliefs are potentially not shared by other professionals, and that this can form a barrier to successful PPI. A recurring theme throughout is that the beliefs and motivations of PPI facilitators do not necessarily match with the beliefs and motivations of their colleagues and that this is where conflict arises. This will be discussed in more depth as the themes are discussed throughout the following sub-sections.

3.4.1.1. Patient stories are powerful

Several professionals and laypeople interviewed described how they believed emotive, real-life stories from patients and carers had significant power in engaging people in conversations about patient experience. This demonstrated that those interviewed value the lived experiences of healthcare services, acknowledging that patients possessed something professionals (usually) do not have – experiential knowledge. Another acknowledgement by staff was that patients will use much more powerful and emotive language than they would as professionals, presenting information in a more real-life, storytelling style, instead of the formal nature in which reports are presented. Some also highlighted that storytelling gave professionals an opportunity to simply sit and listen to their patients, instead of being focused on treating them, as demonstrated in the quotes below.

“Yeah, so what happens is, for example, we had a lady who was still on a mental health ward, she’d been detained but she was coming to the end of her stay and we said to her “Look, the Board would be really interested in what it’s like, would you be happy to come and talk?” ...She said it in exactly her words, she would swear [smirking]...Because at the time, her experience had been poor...And I think it’s really important that the Board hear it raw. Because obviously when we [managers] write a report, we’ll use language that we think the Board want to hear but actually to have a patient come off a ward and tell them exactly what it’s been like. It is powerful!”

MHT: Manager (non-clinical) (IA002)

“[We’re] very keen to open Board meetings, and the key meetings just below the Board, with a patient story...So what we’re in the process of doing now is creating a library of patient experiences, whether they be good, or whether they be not so good...So you know, it does set the scene for the meeting, even if it’s just the patient’s voice, you can feel the emotion in the voice and it has quite a sobering effect.”

AHFT: Senior Clinician (IC008)

What is intriguing here is that this belief appears to be in conflict with what these participants described as a difficulty balancing personal stories against the bigger picture (as will be described in the next section). This is potentially indicative of the differing views of PPI facilitators and senior managers within these organisations. PPI facilitators place greater value on personal stories than perhaps senior management would (though this cannot be confirmed as not enough senior managers (e.g. Board members) were interviewed). As such, PPI facilitators face difficulty in striking a balance between ensuring patients are able to put forward their personal stories and being able to influence the wider organisations’ priorities.

Going even further than the belief that patient stories are powerful, professionals claimed that patients are at the centre of what they do and that this means they need an active role in both their own care and the development of services. There appeared to be an appreciation that patients have something professionals do not – lived experiences of healthcare, and that this made them an important partner in service developments, as shown in the quotes below.

“I think it’s essential to do [PPI] and I think it’s, the information that we get, it’s really valuable...we ought to be doing it in partnership because they’re not services for me...how do I know what service users want from not going out there and asking, and working in partnership with them? You’d be too naïve to think you know what you’re doing, if you don’t involve service users.”

MHT: Senior Clinician (IA001)

“Patients are our everyday work and they should be central to everything that we do, and it doesn’t matter how busy we are, that person wants the best care and treatment. And that has to be central and key to everything we do, full stop...So I think it’s a partnership...we’ve got to listen to them to get it right.”

AHFT: Senior Clinician (IC008)

The quote below from a service user representative also shows how laypeople view themselves to be important partners. The individual stresses the importance of having professionals and patients working together, emphasising that successful PPI involves partnership, recognising what both parties bring to the conversation.

“And in the end, it doesn’t matter how many times that doctor has done that treatment, it doesn’t mean they know what you feel like. Like I had a mastectomy, if that consultant has still got her breast, she doesn’t know how I feel. So, I’m an expert in that bit of it and...She’s an expert in doing the surgery...We’ve got a partnership going here. And if we could see it like that [in PPI work], that would be helpful. It’s a partnership.”

SE: Service User Representative (IB004)

Patient stories were sometimes used in meetings observed. In one example (see extract below), the members of the group were visibly moved by the story, and many expressed being able to relate to it. It also prompted considerable discussion about multiple agencies being involved in a person’s care. This is further evidence that the people involved in PPI work value patient stories.

“Simon then showed a moving animation based on a real patient’s story to illustrate the problems some people have in accessing the most appropriate care.

The animation featured an elderly woman who had just lost her husband and suffered from a range of health conditions. One day she has a fall and is taken to hospital, where she receives very good care, but then she is back at home feeling lonely and being visited/contacted by numerous services, causing confusion and frightening her. The story was very emotive and all those in attendance were visibly moved by it. Several members of the group said they could relate to the story, and it prompted many to begin discussing the impact of multiple agencies caring for one individual.”

SE: Observation of patient story shown at Patient Experience Group (OB006)

3.4.1.2. Personal stories versus bigger picture

In contrast to the previous theme regarding the power of personal stories, an interesting finding across all three sites was the evident conflict between personal stories and ‘the bigger picture’ (i.e. the wider organisation and its services). There were suggestions that personal stories sometimes didn’t have relevance to their policies and remit. During observations (examples below), there were instances where PPI facilitators and other professionals referred to organisational policies and their specific powers as reasons for limiting personal stories, or requesting that they be retracted altogether. If a layperson or patient representative began relaying a personal complaint, most professionals responded by claiming that this activity was not the correct forum for such matters, and/or pointing out their irrelevance to the topic under discussion at the time.

“Keith [Carer rep] then interrupted and started complaining about the booking system...He was visibly annoyed, waving his arms at times and talking loudly. The podiatry manager realised he was talking about booking through his GP and said that it’s out of SE’s control. Keith was annoyed at being dismissed like this and said “what’s the point of this patient experience group then?” Mark [Chair] tried to explain that GP’s booking systems are nothing to do with SE but Keith kept pointing out that it’s all NHS. Mark had to ask him to please stop talking about it so they could move on to the next query. Keith was visibly unhappy, frowning and sighing.”

SE: Discussion regarding booking appointments at Patient Experience Group (OB003)

“Rita [a Governor] raised a specific case as a major concern. A lady she knew personally nearly died because of poor diagnostics...John [Chair] asked if this was a formal complaint. Rita said she had advised the lady to make a formal complaint due to the severity. Julie [a senior nurse] then commented that they couldn’t discuss any further here until they’d had the proper complaint and could investigate it fully. Rita appeared to reluctantly agree to close the discussion there.”

AHFT: Discussion regarding diagnostics at Patient Experience & Engagement Group (OC001)

On occasion, a layperson’s opinions were not even based on real experiences, but rather hearsay or general perceptions, as shown in the observation extract below. This also often provoked professionals to be rather dismissive.

“Barry [Patient rep] then wanted to share some thoughts with the group. He had no specific story to cite but made a series of claims about general attitudes of staff, bedside-manner and communication problems. He talked about feeling there was a lack of compassion and care amongst front line staff members these days – a general cultural issue. He talked at length about this and so Mark [Chair] asked for any specific examples him or his family had experienced. He couldn’t give anything specific off-hand but felt there was a general decline in the behaviours and attitudes of front line staff. Mark then asked that they move on to discussing real experiences.”

SE: Discussion about quality of care at Patient Experience Group (OB001)

During interviews, many professionals described trying to strike a balance between listening to personal experiences of patients and their carers, and improving and developing services for the wider populations’ benefit, as illustrated in the quote below. There was an apparent tension in some of the professionals’ descriptions between needing to know personal stories and managing the wider goals. The usual goal of the activity was to improve services so professionals reported being conscious that they needed to be able to extrapolate individual experiences and apply them to the service for the benefit of all. This meant they had to be cautious in using an individual’s experience to influence a service change.

“there’s a fear sometimes...that they’re going to bring personal experiences to the table. And again, it’s a balance, because you do want people to bring personal experiences; [but] not going into the detail. But the only way we learn and make things better is to hear about some of those experiences.”

Case Site A: Manager (non-clinical) (IA003)

“We’ve got to set out the rules of engagement so it doesn’t become personal. So that it actually is thinking in the wider look at the service provision rather than the individual service provision.”

AHFT: Senior Clinician (IC008)

Interestingly, even some of the laypeople interviewed were also aware of the need to balance between personal stories and the bigger picture, as shown in the quote below. The suggestion here is that some laypeople perceived other lay members of having a personal agenda. One might argue that all laypeople who get involved in PPI are ultimately involved for personal reasons and gains (as found in the literature – see section 1.3.1.). However, the perception here may go beyond that in suggesting that laypeople should extrapolate their own personal experiences to the wider picture before getting involved. Those laypeople that make this claim may view themselves as more capable of this than others. This reveals an interesting conflict between the different types of laypeople who participate in these activities.

“You get a group of people in the room and, again, many groups work like this, don’t they? You get the same people all the time, the same points of view, and a lot of people talk about their personal stuff; they don’t look at bigger things...and you have to be careful managing all of that stuff. So, people do it for personal gains.”

SE: Service User Representative (IB004)

3.4.1.3. Personal definition of PPI

PPI facilitators were specifically asked how they defined PPI and what it meant to them. The accounts given were markedly similar to ideas expressed in various PPI models in the wider literature (see section 1.6.). One professional (IB007) even explicitly referred to ‘Hart’s ladder’ (1992, based on Arnstein’s original ladder concept in 1969) as his basis for his

definition of PPI. Although many described PPI in terms of ‘levels’, much like some academics have, what differed in their accounts was that every level has its own value and purpose, as demonstrated in the quotes below. In contrast, some academic models have described ‘levels’ of involvement in hierarchical terms, making suggestions that the lower levels are less valuable and even ‘tokenistic’ or ‘deceptive’ (see section 1.6.2.). The other finding from professionals’ definitions of PPI was how abstract the concept is. They described the overall ideas in a rather vague manner, suggesting they themselves view it as a complex and not easily defined concept. They also used terms rather interchangeably, further demonstrating difficulty in defining PPI. This will be returned to in the Discussion sections.

“I think there’s many, many different levels of participation, and I always use the Hart’s ladder of participation...I think there’s different ways of being able to participate, through complaints, through surveys, coming to meetings, just coming and putting in the suggestion box is participation, and I think it’s got to be formally recognised at all levels.”

SE: Support staff (IB007)

“I suppose, from my perspective, they are different. Engagement, involvement, participation, are all different. They’re all part of the same continuum or part of a cycle, however you want to view it, I think you could view it as both a continuum and a cycle...[at] that top level...how are we involving people on strategy? Then you take it down a level, how are we talking about involving, engaging and creating participation on a service level, but actually, what about involving and engaging and creating participation on a one-to-one level? You know, as a clinician, working with the patient, how are you engaging, how are you involving them in their own care?”

AHFT: Senior Manager (non-clinical) (IC002)

PPI facilitators’ reasoning regarding types of PPI were similar to how researchers design research studies. No one method was deemed more effective than another, and was instead based on different circumstances. Research methods are chosen based on what is most suitable for the target population of participants and the objectives of the research. PPI facilitators seemed to apply the same logic to defining types of PPI.

3.4.2. Motivations

This set of themes are from descriptions of what individuals defined as their motivations for PPI. Laypeople were motivated by wishing to ‘speak out’ for others, and all had personal experiences of oppression or suffering of some form. This very much supports findings from previous research (see section 1.3.1.). However, very little research has explored the motivations of PPI facilitators (see section 1.3.2). PPI facilitators described being motivated by their desire to speak out for vulnerable groups of society, in much the same way as the laypeople interviewed, and many had prior experience working with vulnerable groups. As PPI facilitators and laypeople had very similar experiences and ideals that motivated them, this challenges the assumption that professionals and laypeople will experience power conflicts due to their opposing identities and motivations (see section 1.3.4.). The present research found that conflicts were reportedly more common between PPI facilitators and other staff, rather than with laypeople.

3.4.2.1. Advocacy

Both PPI facilitators and laypeople described a key motivating factor as a desire to ‘speak out’ for certain groups of society. For laypeople, unsurprisingly, this desire was reportedly rooted in prior personal experiences (see next section for further descriptions), whereas professionals tended to draw their motivation to advocate for people based on prior work experience dealing with marginalised groups (see section 3.3.4.5. for more on this theme). So, although their life and work experiences may have been quite different, both PPI facilitators and laypeople had an altruistic motivation to help others and make a difference – this seemed to be what drove them. These motivations are demonstrated in the quotes below from both professionals and laypeople.

“You know, whenever I deal with something...I always see the other side, because whenever decisions are made, no matter what decision’s been made, it’s going to impact on somebody, you need to think about how that’s going to go...I always try to, whenever I’m feeding anything back from our complaints, I say “Right, we need to use this and look at how we can improve this.””

SE: Support Staff (IB001)

“I just wanted to help someone else. I don’t want anyone else to go through it. And I thought I could talk to people to say “I’m nothing to do with the hospital,

I'm just here to talk to you. Tell me what you feel." ...Even if I only help them get one thing right, I'll be happy."

AHFT: Carer Representative (IC005)

It could be argued, however, that people in general are never completely altruistic in their motivations, and that their motivations are more about their own personal gains. In a later section (section 3.5.1.), one of the outcomes of PPI is its effect on individuals, particularly laypeople. Some laypeople described how PPI was like a form of therapy for them – that it was cathartic to get involved in PPI activities.

3.4.2.2. Personal interests and experiences

Personal experiences appeared to influence people's expressed motivations, particularly those of laypeople. Personal experiences and interests were sometimes expressed as motivations for professionals as well, as shown in the first quote below. For laypeople in particular, witnessing or being victim to poor treatment and care was reportedly a motivating factor for their involvement. As already described, a desire to 'speak out' motivated them, and this desire was driven by their own personal experiences of adversity, persecution or even abuse.

"Now throughout my complaints [about wife's poor care], I made it clear I wasn't looking for retribution, or heads on plates or compensation; I just wanted to see things improve and I would do anything I could to help that process. And through that I was invited onto the improving your experience programme...I felt it was almost my vocation to, or duty almost to my wife, to push these things and get involved."

MHT: Carer Representative (IA007)

"And with my mother who died a couple of years ago, she had Alzheimer's. You remember that video? [referring to a patient story shown at a recent meeting] Well that was exactly my story. I was the daughter, my mother was widowed, Alzheimer's, she lived 100 miles away; so, I've gone through all of that process...So when I saw that story; that could be me and my mum. And me and many others as well."

SE: Service User Representative (IB004)

As you will see from a later section, professionals tended to be more motivated by their work-related experiences rather than personal ones – for example, working with marginalised groups in the past and having a desire to improve services for that section of society. In both the cases of laypeople and professionals, the key to motivations seemed to be exposure to poor care, discrimination, or even physical harm, either as a self-experienced incident or a witnessed incident.

3.4.3. Personal barriers

This section describes barriers that professionals and laypeople described as either personal to them or to others. During interviews, participants were asked to describe their own personal barriers (if they had any) and barriers for others in getting involved in PPI activities. Apathy, anxiety and a lack of skills and confidence were all described as barriers that either affected them or others. PPI facilitators talked in depth about a variety of barriers (some of which have already been described under ‘Organisational factors’). The detail by which they were able to describe the personal barriers of others suggests they may have a deeper connection with the subject of PPI and its complexities than perhaps others do. A major finding of this research has been the importance of the role of PPI facilitators – given their similar experiences and motivations, one could argue they have a deep connection with laypeople (this will be returned to in sections 4.4.2. and 4.9.).

3.4.3.1. Apathy or lack of awareness

Some professionals described how some front-line staff, particularly clinicians, may not engage in PPI activities or acknowledge the importance of PPI simply because of ‘apathy’, as demonstrated in the two quotes below. PPI facilitators described how they had experienced dealing with front line clinicians (and sometimes managers as well) who simply hadn’t considered why PPI may be something they needed to consider in, for example, a service change they were implementing. They didn’t describe this in terms of a deliberate attempt of front line clinicians to exclude patients and the public, but simply lack of awareness of the importance, as shown in the quotes below.

“I want a massive campaign to go out around raising awareness of...it’s not just about involvement of somebody in their own care plan; it’s about, as a team, “how are you involving them as a stakeholder in that service?” ...[PPI]’s just not

even something that occurs to them to do, because it's just not something they've ever talked about I guess."

MHT: Manager (non-clinical) (IA002)

"Sometimes I think it's apathy. Some staff just don't think [PPI is] important. I would say that's a minority. I think most people know, because we're all recipients of services, service change can affect everyone."

SE: Senior Manager (non-clinical) (IB002)

Interestingly, some interviewees (both professionals and laypeople) also described how there can be apathy in patients and the public when it comes to getting involved in PPI activities (as shown in the quotes below). This in itself presents a barrier for PPI facilitators in trying to engage patients and the public. This also links with the issue of representativeness, which was described earlier in section 3.1.5. A key problem that professionals identified was the fact that only a small group of individuals tend to be willing to get involved in PPI activities, and this inhibited PPI facilitators' abilities to engage on a wider scale.

"There's always barriers...patients not wanting to be involved with certain things, so you really need some information on something, but people haven't got the time or the interest, so it's what do you do then?"

SE: Support Staff (IB001)

"if they're [the public] not ill they don't want to know, they don't want to get involved, and I think that's the difficulty when they're in hospital or in primary care, they don't want to get involved until they need you [laughing]."

AHFT: Governor (IC001)

3.4.3.2. Fear of involving patients and the public

Some professionals described how a barrier for front line clinicians and managers can be anxiety or fear about what PPI involves. Sometimes professionals were reportedly fearful of what laypeople (particularly patients who they know may have experienced poor care) will say and whether they will be able to respond appropriately. In the next section, personal skills and how they contribute to successful PPI will also be described – a lack of confidence by

staff may be at least partly contributing to their fear of involving patients and the public. Professionals interviewed also described how some front-line staff and service managers worry that involving patients and the public will mean that their own plans will get “overturned” (IA002), as shown in the two quotes below. This demonstrates what could be argued to be an attempt to maintain some power in decision-making about how services should be run.

It is important to note here that the professionals interviewed were not describing their own anxieties, but instead speculating about what anxieties other professionals may have. Again, this reiterates how the role of PPI facilitators involves a mediatory element. Part of their role was reportedly to allay some of the anxieties front-line staff and managers may have about bringing laypeople into discussions about service developments.

“Barriers to staff doing it, they think their wonderful plans will get overturned so they don’t want to go and open a can of worms. They’re worried about managing expectations, they think it’s going to be really hard work, they don’t really understand what they’re supposed to do.”

MHT: Manager (non-clinical) (IA002)

“Part of that [lack of involvement] is, if you [a service manager] believe a course of action is right and then you ask lots of people and they say not, people generally don’t like being told that what they want to do they shouldn’t do, especially a senior manager.”

MHT: Senior Manager (non-clinical) (IA006)

Some PPI facilitators also acknowledged that, at times, front line clinicians in particular were fearful of giving away information that might indicate the quality of services is not as high as it could be. The issue of transparency and accountability has already been discussed, but it seems front line clinicians may be fearful of letting the public see that not all services are of a high quality. It is possible that, because of the intense media attention on the NHS, professionals working in these organisations feel pressure to maintain the appearance that their services are working well. There was indeed some mention of media influence in interviews. However, there was an insufficient quantity of data to support the discussion of this issue as a theme.

“And I know from previous bits of work I’ve been involved in, clinicians can be very wary about involving service users and carers... [They say] “Ooh, we can’t tell people that”, and not wanting to air your dirty washing.”

MHT: Manager (non-clinical) (IA003)

There were some professionals who also suggested that clinicians and managers may indeed question the value of lay representation on groups or activities, as shown in the two quotes below. They can be ‘wary’ of why the layperson is there and don’t necessarily see the value of their input. PPI facilitators appear to have an understanding beyond this concern, appreciating that service users will not always have the same view as a professional, but that they are equally valuable as already described in section 3.3.1.1.

“I think there’s the cultural thing, in terms of it becoming a normal way of working, because I think people sometimes feel threatened by, sort of, non-experts getting involved in the organisation. “What do these people really know about this? They’re going to slow everything down, they’re getting in our way, they’re asking lots of questions.””

SE: Non-Executive Director (IB008)

“the feedback [from Governors] is that some [staff] absolutely embrace them [on committees], but others are treated with a sort of air of suspicion really. You know, “what are you doing on this group? You don’t work at the hospital, you’re not a nurse, why would you know anything about this?””

AHFT: Manager (non-clinical) (IC009)

3.4.3.3. Lack of skills

PPI facilitators sometimes referred to a lack of skills amongst front line staff as a barrier preventing them from having the confidence to deliver PPI activities. This is potentially related to the above theme – a lack of skills could potentially have led to a lack of confidence and, therefore, an anxiety about getting involved in PPI activities. One PPI facilitator (first quote below) even suggested that some staff members perhaps do not feel empowered enough by senior management in the organisation to get involved in PPI activities and so they shy away from conducting these activities at all.

“With services, often the commitment is there and they’re very passionate about their patients but...Sometimes it’s the skills, you know, to be able to do it effectively, some staff don’t know where to start, and [don’t have] confidence to do that.”

SE: Senior Manager (non-clinical) (IA006)

“[Patient] experience is there, and I think people want to do it, but I don’t think they necessarily know how or what [to do]. Maybe they don’t feel empowered that the changes will do the improvements.”

AHFT: Senior Manager (non-clinical) (IC006)

This suggests that PPI work in organisations falls on a small number of individuals, rather than on multiple employees across the organisation. In section 3.2.1.3., the issue of the need to engage front line staff was highlighted, and PPI facilitators suggested there needed to be more ownership of PPI at service-level for it to be successful. They suggested this because of a perception they themselves are too distanced from services to enact change. However, if front-line staff do not have the skills to conduct PPI activities, the work will likely continue to fall on those in central PPI facilitator roles. These issues are part of a wider organisational dilemma of having a top-down approach, where central managers conduct this work on behalf of service staff; or a bottom-up approach, where front-line staff are given responsibility to conduct the work at their own service-level. This tension between top-down and bottom-up management will be returned to in section 4.7.1. of the Discussion.

3.4.4. Personal skills

PPI facilitators and laypeople both made references to their individual skills – skills which they felt aided them in PPI activities. Some of the key skills described were strong communication skills, confidence in speaking out and/or dealing with conflict, integrity and honesty, and an ability to network and maintain relationships. Equally, they also acknowledged what skills others may need if they wanted to conduct or get involved in PPI activities successfully.

What is particularly interesting about the skills described is that they are seen as equally important for PPI facilitators *and* laypeople. They are not only motivated in similar ways, but they also display the same skills and attributes. This may be suggestive that PPI facilitators

and laypeople are closely aligned in their motivations and behaviours, perhaps in conflict with other stakeholders such as front-line clinicians. This places PPI facilitators in a uniquely challenging role. It is this challenging brokering and negotiating role that is the core of this research – this will be returned to in section 4.9.

3.4.4.1. Communication skills

Unsurprisingly, as PPI activities inherently involve social contact and deliberation about various important topics, communication skills were referenced by both laypeople and professionals as an important attribute. They acknowledged that their own strong communication skills aided them in PPI activities. Professionals described how they felt their good communication skills were important for their role, as demonstrated in the quote below. This supports findings in PPI literature (see section 1.4.6.).

“[I wanted to] use the skills I have talking to patients and making things better rather than talking about it to other people [in academic capacity]. It was about actually being able to do that.”

AHFT: Senior Manager (non-clinical) (IC002)

Laypeople also suggested that their communication skills were important in successfully participating in PPI activities. However, as demonstrated in the quote below, the risk of having such good communication skills and confidence in talking to professionals was that professionals would no longer view them as a layperson. As the person quoted below suggests, they can be seen as a “professional patient” (IB004). This also feeds into the issue of representativeness discussed at length in the literature (see section 1.2.1.).

“Well I know from past experience...I will be treated differently because I come across as a professional. Because I can talk like this and because I have confidence. I’m what you might call a professional patient, in that sense...I know how to talk to people at all levels and that’s because I’ve done it all my life as part of my work.”

SE: Service User Representative (IB004)

Observations of activities also highlighted how important effective communication skills were, particularly of the individual chairing or facilitating an activity. PPI facilitators

needed to be able to translate information into easily understandable language for laypeople, and ensure that each participant had an opportunity to contribute. Often other professionals would speak in technical terms, presenting a barrier for laypeople to get involved in the conversation. PPI facilitators were key in translating and aiding the conversation for laypeople, as shown in the observation extracts below.

“At the last meeting, there had reportedly been a discussion about what information should go to the Quality Assurance Committee (QAC). Gerald said he didn’t understand what they were talking about, so Catherine clarified that there was concern from QAC that there weren’t enough details in reports to provide them with the assurance that things were being dealt with operationally.”

MHT: Discussion about reports at governance meeting (OA006)

“Sharon was an excellent facilitator who ensured everyone had their say by asking each individual to share their view. She helped to steer the group to think about solutions and positive elements instead of letting the negatives swallow up the conversation. She did this by asking for suggestions after each negative experience was shared.”

AHFT: Focus group with fibromyalgia patients (OC011)

3.4.4.2. Integrity and honesty

Closely related to the previous theme, is the reported need to practice with integrity and honesty. PPI facilitators described being aware that, sometimes, PPI activities are conducted in a less-than-honest way. As already described, some PPI activities were deemed to be a waste of time altogether because the organisation was already bound by a policy or national initiative. Some PPI facilitators described feeling that this deceives the public into believing they have a greater influence than they really do.

As such, PPI facilitators reported believing they needed to not only have a clear mind on the purpose and intended outcomes, but that this also needed to be set out from the beginning in an honest and open way. Some specific examples were given by PPI facilitators (two provided below), such as instances when clinics or facilities must be closed or scaled back because of a lack of funding. The outcome is, therefore, set out from the beginning without much room for negotiation but the way in which that change occurs can still involve

patients and the public. PPI facilitators explained that, in these sorts of circumstances, participants need to understand the reality of the situation and their role to avoid feeling deceived or under-valued.

“An example is, we had a service that we were going to have to maybe change, because there simply wasn’t enough money to carry on doing it as we were. Those patients that we thought were going to completely hate us actually completely understood what we were doing...if you’re honest and you’re open, and you involve people at the right time, actually they can be a really useful force...They can advocate on your behalf [to the commissioners].”

MHT: Manager (non-clinical) (IA002)

“We can say we can only offer these options because of limited capacity, and say “Well you tell us what would be your priority? Tell us what would give you the most for the least buck?” ...It’s that feedback between the two because if you listen, but if you’re not actually going to take that on board and feedback what you can and what you can’t do as well, then you don’t build that relationship and that trust.”

AHFT: Senior Manager (non-clinical) (IC007)

In some observations, there was also evidence that PPI facilitators were being open and honest with participants, which they in turn appreciated, as shown in the observation extract below.

“Sharon was also frank and honest about sensitive issues and how the Trust could or couldn’t help them in times of austerity. She was also honest at the end that she couldn’t promise a support group would be set up and it would depend on funding available. The group members all reported that they appreciated her honesty.”

AHFT: Focus group with fibromyalgia patients (OC011)

This all again contributes to the ongoing theme throughout this research of the negotiator/broker role PPI facilitators play between the organisations they work for, and

patients and the public. The quote below articulates how they felt that a key part of their role was to be honest with laypeople about the reality of the extent of their influence and role.

“So, if [service managers] cock it up, if they don’t deliver, you go down with the ship. And it damages your relationship with communities as well. I kind of got around that by being very honest and open; more honest and open than the organisations I worked for would permit. But it meant that, that the level of honesty, meant that I had the level of trust.”

AHFT: Support Staff (IC003)

3.4.4.3. Relationship Management

Related to the above theme was the importance of relationship management. There was an acknowledgement from both PPI facilitators and laypeople that constructive relationships were very important for PPI to be a success (or even for it to happen at all). Not only did they claim that relationships were important, they also stressed the importance of *maintaining* those relationships. This has also been reported in the wider literature (see section 1.4.6.) Some PPI facilitators specifically expressed that their skills in maintaining relationships and building a rapport with people had aided them in their role.

“What I’ve done is make sure that I’ve kept in contact [with community leaders], that I’ve shared information that I feel they need to know. If ever they’ve had a question, even if it’s something I can’t deal with, I’ve encouraged them to come to me and I’ve made sure I’ve got the answers. So, it’s been about building trust.”

MHT: Manager (non-clinical) (IA002)

“One of the biggest issues, I learnt, that makes effective engagement, is relationships. If there is no relationship with somebody, either on an individual level or a group level, or even a community level, it’s the “who the hell are you?” syndrome. “Why should I trust you?” ...and I know that one of the things that meant I was good at engagement, whether or not I had the skills, is just I had a history with people. It’s that I’ve been working with these communities for 10 years. So, they knew me and I knew who to go to.”

AHFT: Support Staff (IC003)

Equally, the laypeople interviewed also talked about how important it was for them to build a rapport and good relationship with professionals, as demonstrated in the quote below, which describes relationships breaking down. Both laypeople and PPI facilitators described instances where relationships had broken down for various reasons in the past between organisations and communities, and suggested this then led to a lack of successful PPI. To overcome this issue, relationships had to be rebuilt, as already shown in the quotes above from professionals and the quote below from a layperson.

“You’ve got them to talk to a group, she or he knows exactly how to deal with a group and then they go and promote them! And you never see them again! They get somebody else in there [snaps his fingers] and you start again! ...That’s the frustrating part because the people that come into these groups are usually that good they get promoted up or...they’ve all been made redundant because of the cut backs! Either way, they’ve gone.”

SE: Carer Representative (IB003)

3.4.4.4. Networking

Both PPI facilitators and lay representatives referred to and described practices of networking. PPI facilitators described this in relation to recruiting lay representatives for projects or committees – they actively utilised existing relationships they had with various external groups or organisations, or simply approached lay representatives whom were already involved in PPI activities elsewhere.

It is this networking practice that some may argue contributes to the issue of exclusion. By contacting existing groups and existing PPI participants, staff are actively excluding those who have not already got involved in PPI activities. This could be argued to be a way in which organisations maintain power – by only recruiting those they already have allegiances with. They may do this because they wish to recruit those who will aid them in making their own plans a reality. However, the reflections of participants in this study suggests the process of recruitment is complex and affected by so many factors (most of which are practical issues), that actually it is difficult to not appear exclusionary.

The quotes below from professionals describe their strategies for recruiting PPI participants by utilising existing contacts. You may note that these professionals are

describing these practices in very pragmatic terms, indicating that using existing contacts and networks may be more about practicalities than an effort to actively exclude others.

“[We’ve utilised] people that have been doing this for a number of years and people that are able to sit at various groups. They’ve had training. They’ve got good support. You can’t just ask somebody to come along. People have got to have the right support...because it’s quite a daunting prospect sitting with a bunch of professionals.”

MHT: Manager (non-clinical) (IA003)

“One of my suggestions would be, again, it’s about getting the right people involved. But also, how does that patient then link with other groups so that we’ve got that wider involvement...how does that then feed into other groups as well so you get that real voice? To get representation of the wider community.”

SE: Senior Manager (non-clinical) (IB002)

Although most professionals described networking in very pragmatic terms, one professional seemed to be making the observation that they see ‘the same faces’ at multiple activities, using the specific example of HealthWatch members. Although this individual did not explicitly describe this as a negative issue, there was some suggestion in her account that it may sometimes present conflicts of interest. The organisation had put in place a policy that Governors could not also be HealthWatch members, because of the potential conflict of interest, but they hadn’t put any restrictions in other less formal PPI activities. This shows that there is some awareness of the potential downsides of the same laypeople being involved in multiple roles, and yet many PPI facilitators openly described utilising these existing contacts for multiple roles and activities.

“They come to our Board meetings, or rather a representative from HealthWatch, comes to our Board meetings...[But] any Governor [of our organisation] is not allowed to be a Board member of HealthWatch...I would imagine amongst the membership [of our organisation], there will be HealthWatch members, and when we have our Governors meeting, they’ll be public, so anybody could come along, so it may be that the HealthWatch come along to those as well.”

MHT: Manager (non-clinical) (IA008)

Laypeople were similar to PPI facilitators in that they built up contacts and joined multiple groups in a snowballing effect – one project or group led them to join other activities. Indeed, every PPI activity that was observed involved laypeople who were either also seen in other activities or they mentioned other groups and activities they were involved in. Almost all laypeople who worked with these organisations were also members of community groups, charitable organisations, or advocacy organisations. This shows how these groups and committees can involve what is actually a very small network of individuals that do not necessarily represent the wider community. This issue will be returned to in section 4.5.3.

“I got involved in a couple of other projects with [the Trust]. Then one of my colleagues [at charitable organisation] was involved in the [project name] and she was talking to me about it and I simply emailed [the Project Lead] and asked can I get involved? And it’s because anything that’s going to help carers has got to be good...and many of us [carers] are also campaigning.”

MHT: Carer Representative (IA007)

“I think [SE] had a community thing at the [local shopping mall]. You know, there were stalls with all kinds of things on. And because I’ve got contacts, you know, people that I’ve known from different sectors in the past...and there was a woman I knew was actually doing a health store...so we had a chat...So that’s how I got involved.”

SE: Service User Representative (IB004)

3.4.4.5. Related previous work experience

Previously, in section 3.3.2.2., it was discussed that work-related experiences had motivated PPI facilitators, as opposed to personal experiences, as was the motivating factor for laypeople. This section describes how both PPI facilitators’ and laypersons’ previous work experiences were acknowledged as being instrumental in equipping them with the skills required for PPI activities and roles. PPI facilitators interviewed all had experience of supporting and promoting the rights of marginalised groups – they had strong social justice motivations born out of their experiences in previous roles. They described carrying these skills and experiences through with them to PPI roles.

“I started as a support therapist working for a challenging behaviour service down in the South West...and then moved into PALS [Patient Advice & Liaison Service] ...what I liked about PALS was people would come and see us with really serious concerns...you get the option to try and sort it and there’s a decent chance of it being resolved...but then this post came up in patient experience, which was exactly what I loved most about PALS.”

MHT: Support Staff (non-clinical) (IA009)

“Well my professional background is social work...So I worked in social care...there were lots of, sort of, projects, managing community development, setting up programmes around health promotion, health prevention. Quite a lot of work in the voluntary sector, which connected me with a lot of community leaders, seldom heard groups, you know, that’s the kind of strength I bring into the role really.”

SE: Senior Manager (non-clinical) (IB003)

Laypeople often came from professional backgrounds, particularly public and third sector roles – teachers, healthcare workers, social workers, etc. They described these experiences as helping them to be seen as an equal to professionals – they could speak the same sort of language as professionals, they shared similar work experiences, and had shared knowledge. This is demonstrated in the quote below. As already described, this feeds into the concept of there being professional laypeople, contributing to the issue of representativeness discussed in the literature (section 1.2.1.).

“Basically, I started as a teacher and I took those experiences and skills into the other sectors, into the third sector and into housing. So, you can see how it all works? I have now retired from paid work, but I looked for some of the things I could get involved in, again as a volunteer, so that’s how I got involved in PEG [Patient Experience Group].”

SE: Service User Representative (IB004)

3.5. Logistical and practical factors

This section describes logistical factors involved in the practice of PPI work. The methods of PPI activities, how participants are recruited, and the practicalities of locations and timings can potentially play a considerable role in how effective PPI is. PPI facilitators, various professionals, and laypeople all detailed accounts of the practicalities of PPI. It was clear from these descriptions that PPI can be complex work on a practical level. The wider literature on PPI has often argued that professionals make attempts to maintain power, either consciously or unconsciously, by setting agendas and making key decisions (see section 1.3.4.). However, the present study does not make these assertions, particularly as many of the professionals interviewed were PPI facilitators whom make attempts to remove barriers to PPI.

3.5.1. Methods of involvement

This section describes the methods by which staff involved patients and the public. The accounts from participants support previous research which shows that the most popular method (and arguably the least engaging method) was surveys (see section 1.4.1.). Reflecting some of the barriers already described, it is entirely understandable that organisations would frequently use surveys rather than more qualitative methods – there are time pressures, a lack of resources, and competing priorities. Surveys are a quick and simple method of gauging patient and public opinion, which can then be fed into service developments. The second most common method appeared to be the setting up of panels or groups made up of laypeople and professionals. Other methods utilised less frequently were focus groups and interviews.

The professionals interviewed (particularly those from core PPI roles) recognised that a range of methods need to be employed to engage with different groups and to meet a range of purposes. The phrase “you can’t be a one-trick pony” (IC002) was used to describe the general approach to PPI. Professionals described having an understanding that different target groups required different methods. The aims and goals of PPI activities also drove choice of method, such as the need to consult a specific group of patients. In cases where there was a specific goal and group of patients targeted, focus groups were more frequently chosen. The notion of targeting methods at specific groups will be discussed in more detail in section 3.4.4. The following quotes from professionals contain descriptions of the range of methods they use and why a range of methods was deemed to be important.

“If we’re going to get real engagement, involvement and really hear that voice, we’ve got to have so many different methods of doing that. The Patient Experience Group being one of them, engaging with different groups being another, complaints being another, ensuring that we get the right representation on our committees.”

SE: Senior Manager (non-clinical) (IB002)

“I call it the kind of hierarchy, you know, like a pyramid in a way. And the pyramid is based on a number of things, so volume of people and topics. You know, so the bottom of the pyramid is the biggest volume and the broadest topic. The further up you go, you get more specific, and therefore, the group [being consulted] also becomes more defined. And up the side of that pyramid is the different techniques to do that...So you can’t be like a one-trick pony.”

AHFT: Senior Manager (non-clinical) (IC002)

Another key issue is that Government bodies require some specific healthcare surveys to be completed. This reportedly limits how varied organisations can be in how they involve their patients and the public. Professionals claimed this sometimes leads to efforts to adapt imposed methods to make them more meaningful for their own patients. Frustrations regarding this were reported by many professionals during interviews but was also something openly complained about in meetings and PPI activities, as shown in the example observation extract below. Furthermore, there were references in observations to the inappropriate application of the FFT. As a prime example, the extract below indicates this.

Chloe reflected that [the FFT] had had mixed success across the Trust – there had been issues with how appropriate the question is in certain areas...NHS England...was wanting to formally test its value in mental health and community settings. MHT had been selected as a pilot site [to] test out the wording of the question...Michael stressed that they shouldn’t try and force it to work – it needs to really be tested properly...this is their opportunity to influence how it works...Michael then added that the trial is across 100% of MHT’s services, so will include prisoner health, severe mental health inpatients, CAMHS [Child & Adolescent Mental Health Services], etc...Catherine laughed when he mentioned

prisoners and said not only are they highly unlikely to recommend services because they're in prison, they might also use it as a tool to "air all sorts of things". Michael acknowledged that and said "we can only give it a go". Chloe added that there are forensic services as well and high secure units – how appropriate will it be there? ...Michael joked that "In the near future, you might have Ian Brady being asked 'would he recommend the care he's receiving?' I think we all know the answer!"

MHT: Discussion of FFT at corporate governance meeting

This demonstrates how restricting Government policies and guidance can sometimes be when being put into practice. The restrictive nature of these policies means that staff, but PPI facilitators in particular, do not have the power to conduct PPI activities in a flexible way. The issues with Government-prescribed methods will be returned to in section 4.3.3.

3.5.2. Practical arrangements

This theme describes some of the practical details PPI facilitators had to consider when planning activities – primarily the 'where' and 'when'. Key considerations regarding time of day, location, facilities, expenses for participants, etc. had to be made when planning PPI activities. The practical barriers have been pointed out in the literature (see section 1.4.4.) and academics have pointed to the potential to exclude certain groups – for example, by holding a project meeting during the day on a week day inevitably excludes those who are working or in full time education. Likewise, holding a meeting in a building with poor wheelchair access will make it difficult for some disabled people to get involved.

Whilst some may argue that these barriers are put up by professionals as a way of exerting authority, the present research does not suggest this. The descriptions by professionals appeared to be very pragmatic in nature, as they described being aware that certain locations and times would exclude certain groups. Their descriptions suggested this was an issue that frustrated them but was perceived to be out of their control. All three organisations had no dedicated budget for conducting PPI activities. This reportedly limited PPI facilitators' choices about where, when, and how to conduct PPI activities. For example, holding a PPI event in a public location outside of core working hours would incur several

costs – fees for renting the facilities, expenses payments for participants, and potential overtime wages for staff.

For NHS organisations with limited budgets, it is not surprising that compromises sometimes had to be made about where and when to hold events. The quotes below illustrate how aware professionals were about logistical issues and how certain decisions about where and when to hold activities will exclude certain groups. They appeared to be regretful about excluding people because of practical issues and gave examples of why it was unavoidable at times (e.g. lack of resources).

“I think there’s going to be an increasing need around involvement to live the way that people live now, which is a 7-day week. People don’t live a Monday to Friday life anymore; it’s sort of a 7-day week. And we’re going to have to think about that, and if you’re holding a consultation, why not hold it on a Saturday?”

MHT: Senior Manager (non-clinical) (IA006)

“[The Patient Experience Group is] run during the day at a certain time; that fits that client group [the elderly], if you like, but it doesn’t fit everybody. I wouldn’t want to encourage young people to come to that group. Because a) they’re elderly, and secondly, we want them to be in school, don’t we?”

SE: Senior Manager (non-clinical) (IB002)

Laypeople were also very aware that certain activities would exclude others. It is worth noting that all the laypeople interviewed were retired or out of work and had no dependents at home; therefore, they had free time during working hours. The carer representatives that were interviewed were also actually no longer carers for various reasons but had felt motivated to represent the carers community. The laypeople interviewed also seemed regretful that many of the people they were representing couldn’t get involved themselves.

“The very nature of the events is most of them are going to be in the daytime because of staffing, and many, many carers are at work, so they can’t always take time off...It’s also an issue that they have to travel into wherever the event is...so it’s difficult.”

MHT: Carer Representative (IA007)

3.5.3. *Methods of recruitment*

This section describes how PPI facilitators and their colleagues recruited participants for their PPI activities. As already described, the people who tended to get involved were a rather homogenous group – retired, middle-class, and white with a professional background (teaching, management, law, politics, etc.), and mostly female with an interest in health. The strategies and methods that PPI facilitators used to recruit participants often meant that this group of individuals was most accessible. The logistical issues already described meant that certain groups were naturally excluded from the activity itself and we have already learned that many practical issues prevented PPI facilitators from getting around these barriers.

However, they did have full control over how they recruit participants. But the methods by which they recruited participants removed the opportunity for certain groups to get involved. The professionals interviewed described how they primarily used existing networks and contacts to recruit participants and most didn't seem to be aware that this strategy could exclude certain groups. They claimed to use existing networks for ease and convenience, as described in the quotes below. The various pressures put on these individuals perhaps go some way to explaining why they feel the need to take easy options. The second quote below is from a support worker describing how they intended to use existing networks for a future project, while being aware this would exclude some of their service users. Interestingly, this individual offered up no alternative recruitment strategies to avoid this issue. This may suggest that these individuals are more pressured by practical constraints than they are by the need to engage with diverse groups.

“So, what we have done with this project is we've gone to our own well-established groups of service users and carers. People that have been doing this for a number of years and people that are able to sit at various groups. They've had training. They've got good support. You can't just ask anybody to come along.”

MHT: Manager (non-clinical) (IA003)

“My plan is to involve members of the Patient Experience Group, some of them; but also to get two of our community groups, and the voluntary sector. What I don't want to happen is that it becomes the same faces...I think the issue is with lots of involvement, your normal age group is quite an older age group, and that

age group is really valuable but it's not representative of the service users as a whole."

SE: Support Staff (IB007)

3.5.4. Targeted and focused projects

We have already learned how PPI facilitators found that they needed to employ a range of methods of PPI. They also argued that the best way to engage certain groups was to conduct targeted and focused activities, as shown in the quotes below. There were four key example activities observed that can be deemed targeted methods. At AHFT, staff conducted a focus group on two key topics – how to support patients dealing with the side effects of chemotherapy, and another on how useful a Self-Management Group would be for people with fibromyalgia. In SE, two focus groups were conducted with two specific service user groups: Polish mothers and families with children with complex conditions accessing Health Visitors services.

"A specific purpose; meaningful engagement...communities and patients get very fed up of being consulted on about lots and lots of things. So, its meaningful engagement...So we will only go out if it's something that we need to be engaging on, like the Health Visiting consultation, and there's a massive programme now around the integration of adult services as well."

SE: Senior Manager (non-clinical) (IB002)

"The cancer group that we've done recently was developed out of the inpatient survey whereby we were still significantly above the national average but we had had a significant decrease from the previous year, so it was still an area that we wanted to focus on and address...So there is learning there even though it was very focused, that actually it's still valuable to the rest of that service and probably valuable to the rest of the organisation as well."

AHFT: Manager (clinical) (IC006)

It is also worth noting that these activities appeared to take considerably more effort and time (and likely costs) than other activities such as surveys and having lay representation at meetings. In all the examples of focus groups, very few participants showed up on the day due to illness or family issues – 3 were missing from the cancer group at AHFT, 2 were

missing from the fibromyalgia group at AHFT, and 3-4 were missing from each of the Health Visiting service focus groups at SE. This demonstrates that, despite focused targeted work, they potentially come with greater challenges, particularly if the target group has a long-term condition. PPI facilitators expressed frustration at these activities, as shown in the observation extract below.

“Kiran explained this was the second time they’d attempted to get a focus group with families who had children with complex needs and disabilities...Unfortunately, after waiting some time, only one family had shown up...Lucy and Kiran chased up other expected participants by phone. Unfortunately, most of them were unable to attend due to illness and problems with their children. Kiran said it’s the same reasons they had last time they tried to do this.”

SE: Focus Group on Health Visiting service (OB005)

3.6. Outcomes and impact

This section describes some of the outcomes and impact of PPI as described by professionals and some laypeople. A key point to note here is the lack of tangible outcomes and descriptions of impact, which either suggests that professionals find it challenging to describe what the impact is, or the impact of PPI is minimal. The latter is the conclusion widely drawn upon in academic research (see section 1.5.). From the data described so far, PPI processes and the beliefs and behaviours of individuals involved are seemingly complex. As such, it's unsurprising for PPI to be limited in its impact, certainly at least in the timeframe this research took place. However, it may also be that the complexities make it difficult for professionals to articulate the impact. These matters will be discussed in more depth in section 4.6.

3.6.1. Impact on individuals

Both professionals and laypeople acknowledged that PPI has an added value of developing people. Professionals acknowledged that the feedback they get from their service users was not just important for service developments, but also for their own professional development, as described in the quote below. They described being able to learn new things from patients and change their behaviours towards them as a result.

“Patients are very important for, not just as a person that I look after, but for my development as well, patient feedback is very important. Sometimes I learn things and sometimes it's about moderating your behaviour. Sometimes you learn new things.”

MHT: Senior Clinician (IA005)

In addition, both professionals and laypeople acknowledged the potential of PPI to help develop laypersons' skills, both for the benefit of the organisation and the benefit of themselves as individuals. Interestingly, when PPI facilitators presented these ideas, there was no suggestion that developing a layperson's skills would somehow hinder their perspective as a layperson (referring here to the phenomenon of professionalisation described in section 1.2.2.). This demonstrates that PPI facilitators are potentially more appreciative of laypersons' views, regardless of whether they appear to be professionalised or not.

“Well for me it’s very cathartic, it makes me feel good to do it. I was starting to suffer. I was suffering the foothills, if you like, of depression; I lacked self-confidence and self-esteem, and by coming to these events, I was always being welcomed and made to feel valuable, and that is a brilliant feeling.”

MHT: Carer & Service User Representative (IA007)

“It’s we gain, they gain, because we’re developing quite a lot of skills and social capital there, and help people get into employment or perhaps they would like to get into more formal work with us as an organisation.”

SE: Senior Manager (non-clinical) (IB002)

3.6.2. Impact on services

As already mentioned, there were a lack of tangible outcomes described by professionals (and none seen during observations of activities). There were some minimal examples, as described below. Some of the literature supports this in suggesting that outcomes of PPI are limited in their impact and lack long-term impact (see section 1.5.). Given that the data collection happened over the course of one year, the potential long-term impact of PPI was not explored and would require a significant follow-up project.

3.6.2.1. Changes to patient information

One of the outcomes of patient and public involvement was regarding changes to information and resources designed for patients. Professionals produce patient information leaflets, videos, and posters, and they are, therefore, sometimes not written in accessible language. Some projects that involved patients and the public brought about changes to patient information for that reason. By seeking feedback from and involving patients and laypeople, professionals can design more layperson-friendly information that will be more effective in delivering important advice and health promotion messages. This is an example of what might be referred to as a ‘quick win’ for professionals.

“We will have better information that service users and carers themselves have been involved in designing accessible information, telling people “...this is what it’s about, this is what it means, this is what will happen, this is the [care] pathway”. It will help to coordinate better information for people.”

MHT: Manager (non-clinical) (IA003)

“The changes to the signage inside the eye clinic was a real plus for us because it gave us the chance to show that a focus group could come in to us, they could make a suggestion, between us we could come up with a design, and then we could promote it. That’s what we did with that one.”

AHFT: Senior Manager (non-clinical) (IC007)

3.6.2.2. Changes to staff training and development

Another frequent outcome of PPI was changes to staff training and development. This was as reported by interviewees and witnessed during observations. This seemed to be a frequent outcome of PPI to make use of patient’s views in a tangible way, but the long-term impact of doing this is not known, as the length of this research was not long enough to explore this. Opting to change staff training potentially demonstrates a belief by managers that changing the way in which staff conduct themselves would improve services. This issue will be returned to in the Discussion, as it suggests patient feedback can sometimes be used as a way of moderating staff behaviours – see section 4.4.2. and 4.6.1.

“So, it’s really using the patient and carer experience to build up, really, a training package. All the points that come out of it are actually being built into the KPIs, and performance reviews. So that’s really, carers want more of this, so in the job description, that goes in. Which has to be a really good step forward.”

MHT: Carer Representative (IA007)

“And the other thing we’ve just done, we had a complaint from a chap with hearing difficulties that when he came to one of our departments, the hearing loop wasn’t switched on. What we found out was the staff there didn’t know what the hearing loop was, so they’d never switched it on. So, we knew immediately that we’d potentially got a training issue.”

AHFT: Senior Manager (non-clinical) (IC007)

3.6.2.3. More efficient service

Although few examples were given of this outcome, professionals described how involving patients and the public had the potential to save resources. They argued that they may sometimes discover that the service being provided is not of real value to patients by talking to them, and find that a more cost-effective alternative is more suitable. However, it is

not possible to argue that efficiency savings are a direct outcome of PPI – this research only found that some individuals reported believing it could make savings.

“But then if you do that [PPI] properly, it’s not wasted time because actually, you know, there might be something you haven’t even seen. So like, they might say, “you know you do that thing for us every single week? It’s a real waste of money, I don’t actually need it or want it.” ...I did an event a couple of years ago where I had service users and professionals sat at the table talking about palliative care and one of the parents said “I was getting oranges from social services, which was fine, and I was getting pears from the [NHS] team, which was ok really. But actually, what I wanted was apples... you were all duplicating.””

MHT: Senior Clinician (IA001)

“If you’ve got a patient member sat there [at Board meetings], an actual patient, you know, issues that are being raised that will directly or indirectly affect patients, it would be brilliant to see that, so they could say “Well actually I object, this would impact on me”, which would maybe stop things getting wasted resources and money, right at the top, it would impact.”

SE: Support Staff (IB001)

Interestingly, in AHFT, a support staff member felt that their organisation’s Board were not currently of the mind-set to consider that involving patients and the public could save them money overall, as described in the quote below. So, whilst this individual argued that PPI could save them money by making services more fit-for-purpose, they were of the view that no one in their organisation was attempting to do this. This contrasts with the other two organisations where PPI facilitators were suggesting that efforts to save money through PPI were already happening, or at least being planned.

“What they [managers] don’t quite get is that, actually, we could improve some of our patient flow, so we could reduce DNAs [Did Not Attends], increase people actually taking control of their own health, we could reduce admissions, and we could improve getting people discharged properly...So we tend to look at what we’re doing wrong, in terms of our processes, but we don’t tend to involve patients in that design. I think we lose money because we don’t engage effectively. And I

don't think managers in this organisation get that concept that there is an opportunity to...save money."

AHFT: Support Staff (IC003)

3.6.2.4. Increased marketability

Another suggested outcome of PPI (or at least a hypothetical outcome) was that of increased marketability. This refers to the concept of increasing the appeal of organisations to attract business. In the case of healthcare organisations, this specifically refers to organisations' success in bidding for service contracts. Some professionals interviewed, particularly PPI facilitators, suggested that PPI can have the added value of increasing their organisations' marketability and competitiveness. Their theory was that, by involving patients and the public in developing services, services will be more fit for purpose and of a higher quality, as well as potentially being better value for money as already described above. As such, services would then be more attractive to commissioners.

"I think [senior managers are] starting to slowly understand the importance of [PPI] in terms of competitive advantage. And that if you've got patients who understand what you're doing and have signed up to what you're doing and you've proven that you're having the on-going discussions with them about that, then it's very difficult for another organisation from outside your area to step in. You get a lot of public support...as long as you're having honest conversations with them, then they have more respect for you than say a Virgin Healthcare or another Trust."

MHT: Manager (non-clinical) (IA002)

"But thinking about who may have had that direct experience or caring for that person or supporting them, if those people are actually involved in shaping how it will work, and sometimes it actually stops you from making mistakes, and that's why I think it's important. And I think it could be really valuable to the organisation in terms of quality of services but also in terms of marketability, standing out from competitors."

SE: Non-Executive Director (IB008)

Furthermore, as the AQP legislation brought in direct competition between providers by allowing patients to choose from a range of local providers for certain services, the professionals interviewed also stressed that being seen to be responsive to the wishes of patients would ensure patients continued to use their services, keeping them in business. This shows how the continued marketisation of healthcare is potentially driving the behaviours of both consumers and healthcare professionals.

“For me, everything we do, if patients weren’t here, we wouldn’t be an organisation, and when things change and other organisations come in with business, [like] Virgin have their healthcare, if people haven’t got a good service, they’re going to leave, so what would the organisation do then? It’s at the core of the organisation to be interactive with patients...and to really show them we care about what they’re giving us and appreciate their views.”

SE: Support Staff (IB001)

However, interestingly, an individual in AHFT expressed the view that AQP and the general increasing competition would not affect how managers engaged with communities in the future. Instead, he suggested all it would mean would be more measurement of patient experience, rather than meaningful involvement of patients and the public in service design. However, it is worth noting that, as an acute healthcare provider, AHFT had much less threat to their services from other providers. For the vast majority of their services, they were the only option locally. As such, the organisation did not need to be as competitive as the other two case sites.

“Well, a number of our services are under threat at the moment because of that [AQP legislation]. Will it make a difference to engagement? No, I don’t believe so...I don’t think it will make a difference to engagement. It might make a difference to our data collection on patient experience, which is already happening because we’re already under pressure [to collect data].”

AHFT: Support Staff (IC003)

3.7. Summary of results

The data analysed here has shown in detail the complexities of PPI – its processes, influences and the roles and perceptions of individuals involved. The data has highlighted the complex nature by which organisations conduct and use PPI, and how their internal structures, policies and cultures influence those processes and the people involved. This was the main aim of the PhD research – to look in depth at PPI processes and the people involved, but through an organisational lens. This is where this research differs somewhat from other PPI research, which has mainly focused on processes and the individuals involved. Research has not previously given a great deal of consideration of the role of organisational policies, structures and cultures, as well as external factors such as the influence of Government policies. As such, this research offers a more detailed picture of how PPI looks in practice in different healthcare organisations.

As a further demonstration of the complexities of PPI and how various factors either inhibit or facilitate PPI, the following vignette from a PPI facilitator describes their experiences, expressing their frustrations about these multiple factors. It articulates the important and challenging role of PPI facilitators in their mediator role between patients and the public, and the organisation they are employed by. The description here, whilst it is particularly critical in its tone, illustrates how PPI facilitators can become frustrated and feel the need to employ behaviours and actions that may not necessarily be in line with the wider organisation's policies and culture. It further suggests how key these individuals are in securing and maintaining relationships with communities, and to some extent playing a key role in managing the organisation's reputation.

“So, my reputation, and the reputation of any engagement lead, is always bound with the people delivering the service. So, if they cock it up, if they don't deliver, you go down with the ship. And it damages your relationship with communities as well. I kind of got around that by being very honest and open, more honest and open than the organisations I worked for would permit. But it meant that, that the level of honesty, meant that I had the level of trust. I would have to say, “I'm sorry, but they're really not interested in delivering on this, but here's where you can go to complain” ...Which meant I had to deal with a lot of, oh, horrendous experiences. And people being seriously let down, particularly where we'd

promised a lot and I'd made those connections [with managers and front-line staff] and then they just wouldn't deliver because it just wasn't a priority.

And it has never been a priority, in any of the NHS organisations that I have worked for; even when there's been Board-level commitment. The challenge comes, always, no matter how committed the Boards are, to what if the community want to make a decision that you don't agree with? And it always falls down at that point. Or they'll even agree it, commit to it, and then something else will change in the system. Because it changes so much because we have so much involvement from the SHA, nationally, or whatever. We'll commit to a particular process; we'll even go with communities sometimes on a particular decision, and then it will get pulled.

But it would hardly ever get to that stage anyway because we'd already made the decision on what we were consulting on. And then the whole time; and I've been in terrible commissioning and service development things; where I'm just thinking "the fact that you're arguing back with the public that they're making the wrong decision means that you've already made your decision so why are you even engaging with them?" What you're talking about is a PR exercise, which is fine, but what communities really don't like is being set up."

AHFT: Support Staff (IC003)

In the Discussion sections that follow, the key findings will be discussed in relation to previous research. The Discussion will also include an explanation of how the different factors appear to connect and influence PPI processes and individuals, resulting in a proposed conceptual framework. There will also be further discussion of the mediator role of PPI facilitators, followed by the implications for further research and practice.

4. Discussion

The structure of the Discussion sections that follow will be set out initially in a similar format to the results sections. Each of the five major theme groups (Political and Societal, Organisational, Individual, Logistical, and Outcomes and Impact, sections 4.2-4.6.) will be discussed separately but with reference to their relationships with other factors. Some themes will be discussed in more depth than others; specifically, those themes that either conflict with or add nuances to existing research, or offer new findings not previously researched. Other findings will be briefly covered where they confirm findings of existing research.

One of the largest sections of the Discussion will be on Organisational Factors, as this is where the main focus of the research was situated. Whilst the present research does look in-depth at individuals (both professionals and laypeople), it does so with an extensive consideration of the potential influences of organisational policies, procedures, strategies, and hierarchies, on both individuals and PPI processes. Equally it explores how individuals are not only influenced by organisational factors (such as reporting structures), but also how they can, or attempt to, influence organisational strategies, policies, and processes relevant to PPI.

There will then be a discussion of the underlying tensions that were apparent in these organisations – top-down versus bottom-up management, individual versus collective needs, and patient experience versus patient involvement (section 4.7.), followed by the development of a conceptual framework (section 4.8.). This has implications for theory in that it will highlight the potential interactions between complex and varying factors, from individual to organisational to societal levels. Following presentation of the conceptual framework, the unique role of PPI facilitators (section 4.9.) will be discussed in relation to managing the multifaceted nature of PPI.

The limitations of the research (section 4.11.) and implications for further research will then follow (section 4.12.), drawing upon the drawbacks of the present study and further questions raised from the data. One question for further research is the potential influence of differing healthcare organisational cultures on PPI, for example. Finally, the implications and recommendations for practice will be presented (section 4.13.), before final conclusions are made (section 4.14.).

4.1. Setting the context – researcher turned practitioner

Before discussing the findings of the research, it is pertinent to set further context by describing the transition from researcher to practitioner already mentioned in the Preface, and how this impacted on the study. An opportunity arose to take on a PPI role in one of the three case study sites. The position became available after the end of the data collection period in 2013, following submission of a report on findings to each organisation. This meant that I moved from researcher-outsider to employee-insider before the PhD research had completed. The timing of employment meant that the writing up of Results and Discussion sections occurred alongside practical application of the findings. This provided an interesting and unique experience that could have either hindered or enhanced writing up the PhD findings.

Firstly, by conducting practical application of the research whilst simultaneously analysing the results, a continually iterative process occurred. Interpretations of the data could be applied instantaneously to practice and, likewise, practical applications added nuances to the analysis process. Writing up the thesis at the same time as working as a practitioner allowed for an ongoing cycle of reflection away from work, and then returning to work with fresh ideas for application. This was a considerable benefit to the analysis process. Some of the accounts participants gave were at times abstract and theoretical. By conducting practical application of the findings daily, these more abstract and theoretical ideas could be explored further. This cycle of developing theory and applying in practice in a continuous cycle is similar to the process of action research (Brannick & Coghlan, 2007).

Furthermore, another benefit of taking employment at one of the case study sites is that it provided an unplanned follow up. By working for one of the organisations and witnessing first-hand how PPI work evolves over an extended period, the longer-term impact of PPI is being examined. Having worked for the organisation for three years at the time this thesis was completed, I can say with some confidence that PPI can have a subtler growing impact on an organisation and the individuals within. What has been witnessed during employment is the changes in conversations about PPI over time. At the risk of sounding clichéd, a ‘buzz’ is forming and spreading throughout the organisation. Staff seem to have a growing appetite for PPI work. Some professionals in MHT alluded to the same subtle changes over time (see section 4.6.2.), but these perspectives could not be backed up by observations at the time. By

obtaining a long-term practitioner post at one of the case sites, I can put some real-time observational evidence to that perspective.

Having said this, these arguments are not intended to underplay the potential negatives associated with being an 'insider'. An article by Brannick & Coghlan (2007) identified four main challenges: access, preunderstanding, role duality, and organisational politics. Being an insider in the present research did not affect access, as data collection occurred before employment began. However, it is acknowledged the other challenges were possible hindrances. In terms of preunderstanding, having been a practitioner before in another organisation, there was already a certain level of understanding of PPI in practice. As already described in the Preface, the frustrations experienced in the role informed some of the research aims, but these aims were further defined through reviewing the existing literature.

Regarding role duality (researcher and employee), this was not an issue that would have affected data collection because of the timings of the employment. However, the dual role of researcher and employee likely affected the write-up, as already described. The continuous cycle of reflection and practice most likely influenced the analysis, though the effect is felt to have been mostly beneficial. The final challenge cited by Brannick & Coghlan (2007) of organisational politics refers to the political implications of research into practice. For researchers who are insiders, this is something that can present a challenge when putting research findings into practice. The challenge, as Brannick & Coghlan (2007) claim, is as follows:

“For insider action researchers, politics is more explicit [than for outsider researchers], and so they need to be prepared to work the political system, which involves balancing the organisation’s formal justification of what it wants in the project with their own tacit personal justification for political activity. Throughout the project, they have to maintain their credibility as an effective driver of change and as an astute political player. The key to this is assessing the power and interests of relevant stakeholders in relation to aspects of the project.”

(p.70)

Though this description is most relevant to researchers who begin and continue as insiders throughout the research process (and therefore need to be aware of the political

implications of observing their colleagues etc.), there were challenges when putting the research findings into practice. In practice, the difficulty was in managing the expectations of managers whom had received my recommendations at the end of the data collection period (see section 4.12. for more on this). To manage expectations about what could be achieved and in what timescales, the recommendations of the initial report were converted into an action plan with clear goals, roles, responsibilities, and timescales set. As Brannick & Coghlan (2007) state above, I assessed the interests of relevant stakeholders and responded accordingly.

On a final note, as employment commenced during the data analysis and write-up processes, maintaining distance to allow for critical examination was a challenge. In practice the potential for this to negatively impact on analysing the data was limited by ensuring there was blocked time in which to separate my practitioner work from my researcher work. For example, one day per week was dedicated to my research and some blocks of time away from practitioner work were also used. This allowed me to mentally separate practice from the analysis process and allow adequate 'head space' for reflecting on and writing up the findings. Furthermore, as two periods of maternity leave were taken during this period, there were further blocks of time away from practice. The physical separation of both forms of work were important for maintaining critical distance.

4.2. Political and Societal factors

Although participants were not asked any specific questions about political and societal influences on PPI, many professionals (and indeed some laypeople) reported perceiving a range of external factors as influential to PPI. Various references to culture and political drivers were also noted during observations. As the NHS is heavily driven by Government policies (and frequent changes thereof), the professionals working within all three organisations reported being aware of the influence Government bodies had, both in general and in relation to PPI work.

As found in the wider literature (see section 1.1.2), participants described a changing political and societal landscape to consumerism that was appearing to influence the way in which staff in healthcare providers and consumers engaged with one another. Most accounts of this landscape related to very recent changes in society in two areas; firstly, changes to political priorities and policies (specifically increased consumer choice and competition, and patient satisfaction measures); and secondly, increased use of technology and social media by consumers, allowing a more ‘real time’ exchange of conversation. The effect of these changes in society appears to be a continually evolving relationship between healthcare providers and consumers, both in how they communicate with, and what they expect of, one another.

4.2.1. *Changing political and societal backdrop*

The professionals working in these organisations were wary of competition, referencing AQP legislation, and PPI facilitators in particular reported that involving patients and the public in service design would give them the edge to ward off that competition. Whilst existing literature points to several ‘purposes’ of PPI, such as quality improvement (see section 1.3.2), there do not appear to be many explicit references to PPI serving as aiding competition. Lightfoot & Sloper (2003) did note a small number of professionals claiming services are more likely to be funded if they involved the patient voice.

This is a relatively new concept that few professionals may have developed an understanding of. Given that PPI facilitators are arguably the most closely connected individuals to PPI, it may be that they are among the few to note this potential benefit of PPI. Other staff members whom are more disconnected from this may not have conceived of the

possibility of improving their competitiveness through PPI. Furthermore, the healthcare industry has not been a particularly competitive market until very recently (see section 1.1.2), therefore, most professionals will likely not have considered how they could be more competitive.

The assumptions relayed by PPI facilitators was that PPI can lead to more innovative service design, more efficient and streamlined services, and a confirmation from the consumer that the service will be satisfactory. The data indicated their view was that forming an alliance with the consumer would make the organisation more likely to successfully bid for services. Barnes et al. (2006) identified that PPI facilitators can be ‘allies’ for patients and the public. However, here the suggestion is the reverse – that patients and the public can be recruited as ‘allies’ by PPI facilitators to increase an organisation’s marketability and maintain their reputation with the public. Indeed, one participant claimed you can get them to “lobby” on your behalf (Interview ID IA002); whilst others used words and phrases such as “ambassadors” (Interview ID IC009 & IC010) and “critical friends” (Interview IDs IA002, IB001, IB002 & IB007). The shift of renewed focus on competitiveness appears to be a new driver for PPI – this issue will be returned to in section 4.3.3.

In addition to the introduction of more competition, a new set of Government targets were introduced that further reflected the move towards a more consumer-led healthcare industry – the ‘Friends & Family Test’ (FFT, see section 1.4.2. for full description). It was met with considerable resistance and controversy from professionals in all three case sites (and reportedly colleagues in other NHS trusts) for two key reasons. Firstly, the wording of the question presented underlying assumptions that did not marry up with the delivery of NHS care – the concept of “recommending” the service seemed to make an assumption there is always choice on the part of the patient, but as one professional put it “choice is a fallacy” (Interview ID IA002) in the NHS. Professionals were concerned patients would find the terminology confusing and would not be able to give valid feedback as a result. This supports findings of the Picker Institute’s review of the FFT (2014).

Secondly, professionals reported concerns about the lack of flexibility of the guidance. The question was to be worded in exactly the required format, even if the patient did not understand the question. There were concerns that people with learning disabilities and children would not understand the question, and alternative tools or ways of phrasing it

needed to be available for it to be applied across all services. This is an example of how the willingness and efforts of professionals to be inclusive in their PPI work can be constrained and restricted by Government policies. As the FFT was also a CQUIN target linked to income (NHS Commissioning Board, 2012), the lack of flexibility with the application was particularly frustrating, as it had implications for income for the organisation.

Furthermore, reportedly in response to pressures to both increased competition and increasing consumer choice, professionals in all three case study sites argued their methods and approaches to PPI needed to keep adapting, going beyond Government targets and formal mechanisms, to capture a wider range of patient voices. PPI facilitators all described how PPI work had been increasing, partly because of increased requirements from Government legislation, as already mentioned, but also increasing requirements from Board members and interest from front line staff. The amount of PPI work being reported to Boards had increased in all three sites, according to the professionals interviewed (though the type of information they required was not in-depth – see section 4.7.3.). This may demonstrate a changing culture within healthcare organisations to one that is increasingly led by consumer wishes. These pressures presented a great challenge for PPI facilitators in that it made their roles unpredictable and complex – these issues will be returned to on a number of occasions throughout this Discussion.

Whilst the long-term impact of PPI on organisational culture was not a research aim of this study, at the very least, it was evident that the patient and public voice was permeating many areas in all three organisations. (Prior to this, patient experience and involvement had reportedly been focused on formal complaints.) This presented big challenges for PPI facilitators in terms of practical workloads, but also in terms of their emotional investment in projects. PPI facilitators reported being frequently frustrated that they could not do more of the work they ‘cared’ about – developmental and service improvement work. The emotional labour of these individuals’ roles will be returned to in section 4.9.

4.2.2. The use of social media and digital technologies

The increased use of technology and social media by consumers has also reportedly had an influence over how PPI is conducted. Now that consumers can more easily both access and review various products and services across the commercial and service sectors, the same behaviours are now being seen by consumers of healthcare. It was reported by participants

that consumers wish to engage with organisations quickly and with ease – something that social media and digital technology offers them. Although the NHS has been generally behind the private sector in making use of digital technologies, many NHS providers are now using these media platforms to communicate with their consumers (Adams, 2011; Ancarani, 2005; Hudson 2015). Patients can book online for various NHS services, they can review them on websites such as NHS Choices, and they can now even Tweet directly with the organisation. As Hudson (2015) points out, social media options such as Twitter open up the conversation between patients/the public and healthcare organisations to a wide audience – Twitter users will have followers who will see the conversation unfold in the public domain.

This represents a key change in the dynamics of the relationship between healthcare organisations and their consumers, in that both the communication methods and nature of conversations is changing. What makes these communications particularly important for organisations is that they are in the public domain, presenting a need to be responsive (particularly if the communication from the consumer is negative) to uphold their reputation (Ancarani, 2005; Hudson, 2015). Digital technologies, it has been argued, have the potential to “enhancing the customer-supplier relationship” (Ancarani, 2005: p.8), and improve transparency (Ancarani, 2005; Bertot et al., 2012; McIvor et al., 2002). PPI facilitators in this study explained how they believed embracing new digital forms of communication would present opportunities to widen PPI, and make connections with groups they had struggled to connect with before (e.g. young people). However, the increased ranges and forms of communication available to patients were increasing demands for PPI facilitators as well as others. Several professionals (and some laypeople) also expressed caution about how much more communication should be made with patients and the public to avoid raising expectations of their already heavily demanded services.

Considering the increased use of digital technology in society, it was observed that all three case sites had put in place methods of communication that utilised these technologies. All three sites had social media accounts (Twitter, Facebook etc.), websites that offered direct contact methods (online forms and email addresses), and AHFT was in the process of implementing text surveys at the time of this research. These changes in communication methods brought about a change in the frequency and types of communication, in that most patient feedback historically came via the formal complaints mechanism. Moving towards digital media communication means that contacts are more instant, frequent, and brief. If we

compare this to the traditional complaints process (which is lengthy and involves detailed communications with the complainant), healthcare organisations are likely seeing a shift in both the frequency and form of communications. Communications are moving from few numbers with in-depth communication, to high numbers with brief communication. As such, whilst on the surface it may seem the organisation is connecting with its community more, the depth and quality of that connection is arguably unlikely to have increased.

These recent societal changes of increased consumer choice and voice appeared to be met with resistance from some individuals in the study. Whilst all interviewees reporting being very supportive of involving patients and the public, several professionals (and even some of the laypeople) were wary of the potential to overwhelm the NHS's already heavy demand, citing social media as driving some of that demand. The suggestion was made by some that if healthcare organisations continue to increase involvement of and communication with patients and the public, their wishes may become wider than the scope of available services. This is something not explicitly referenced in PPI literature, though the Kings Fund (2012) point to the general rising expectations of the public. This potentially brings into question how valued the patient and public voice will be in the long-term. It may be that we will see increases in PPI over the next few years (including through social media) before organisations begin to struggle to match demand and scale back PPI as a result.

Furthermore, this demonstrates the tension between individualism and collectivism discussed in the wider literature (Beresford, 2010; Carr, 2007; Fotaki, 2010). The professionals and managers within these organisations, particularly PPI facilitators, are arguably being pulled between the collective needs of the wider community to make decisions about service provision, and the individual preferences of those patients, carers, and consumers whom are involved in PPI activities. Interestingly, as the means of communication become more accessible to the public, the number of voices being heard (though not necessarily directly responded to) likely increases. As such, the gap between individualistic wishes and collective wishes is likely closing. There are many references to professionals rejecting the lay/patient perspective because it is unrepresentative and singular (Barnes et al., 2006; Hudson, 2015; Learmonth et al., 2008; Martin, 2008a, 2008b; Masters et al., 2002; Renedo & Marston, 2015c; Tait & Lester, 2005), so it may be that professionals find it increasingly difficult to reject it, given that it is now not just a small group of individuals.

Another interesting finding in this study was, despite the increases in surveys being completed generally and the increased utilisation of social media by consumers to put forward their views, there was also a perception reported that people can become ‘surveyed out’. Several individuals reported that, whilst they recognised the need to do more to access a wider range of voices, they also expressed caution at not overburdening people with requests. This perception seems to conflict with other evidence that shows that patients and the public are putting forward their views more frequently (for example, through increased formal complaints, see section 1.2.3.), so not appear to be losing their appetite for giving feedback.

However, there is clearly a difference between people coming forward with their views voluntarily and organisations seeking their views. PPI facilitators may simply be cautious about not asking for too much from an already active public voice. Another possible interpretation here is that PPI facilitators may also be wary that surveys will merely only attract the people who would voluntarily give their views anyway through other forums. As such, this would not necessarily collect the wider and more representative voices they were seeking.

4.2.3. Accountable public services

Alongside the political agenda to increase the patient and public voice, and the rise of the patient and public voice via social media, there has also been increasing pressure from Governments and the public for healthcare organisations to be more open and transparent (see section 1.1.3). The professionals interviewed described their efforts to make the organisation more accountable and transparent to its public in response to these governmental and societal pressures. There were some, however, that appeared to express dissatisfaction with the level of transparency in their organisations.

Participants (particularly PPI facilitators) described how they wished to increase openness and transparency, through a range of methods such as having a lay member at Board meetings. Much of the PPI work in all three case sites was being conducted as part of Government requirements (see also section 4.3.3.), but PPI facilitators did not view these measures as adequate and expressed wishes to go beyond what they viewed to be mere ‘tick-box’ exercises. This demonstrates how the role of PPI facilitators can be important in defining the type and methods of PPI beyond those defined by Government agendas. As PPI

facilitators did not view Government-led projects to be enough, this also suggests they view there to be a disconnect between Government drivers and localised PPI work.

The literature suggests that many PPI activities are indeed tokenistic efforts by organisations to demonstrate they are doing PPI, without being particularly concerned with its purpose or potential impact (Abelson et al., 2003; Day, 2008; Felton & Stickley, 2004; Forrest et al., 2000; Fletcher, 2003; Pickard et al., 2002; Thomas et al., 2010). However, data from interviews and observations suggested that, whilst there were certainly examples of what might be deemed tokenistic activities, the PPI facilitators and their colleagues frequently expressed a desire to do more; and in some instances, were doing more. This demonstrates the key role PPI facilitators appear to have in making PPI activities successful and effective. PPI facilitators' apparent drive to go beyond tick-box exercises has the potential to move their organisations into a position of having more meaningful engagement with their communities. Of course, this depends on whether PPI facilitators can influence senior management and organisational strategies. There are indeed many barriers and obstacles in their way, as will be discussed in the next few sections.

4.3. Organisational factors

Given that the design of this research took an organisational lens on issues that have mainly been researched from the individual or small group perspective, the most significantly nuanced and new findings are regarding organisational factors. Interviews, observations and document reviews yielded information about a large number of factors at an organisational level that appear to have an influence over PPI activities and the individuals involved. Key influencing organisational factors can be grouped into four categories: structures and policies, organisational and PPI strategies (including drivers for PPI), competing priorities, and indicators of organisational culture.

4.3.1. *Structures, hierarchies, and policies*

The three organisations' structures and hierarchies seemed to determine reporting lines, and the roles and work requirements of different professionals, including PPI facilitators. This is in line with what Brooks (2009) describes as the traditional organisational structure: "an organisation is configured into work groups and the reporting and authority relationships that connect individuals and groups together" (p.191). As the organisational structures varied across the three sites (described in section 2.5.2.), the roles and work of professionals varied as well. Roles and work tasks were defined according to the requirements of the relevant reporting-line managers and directors, as well as Government directives. PPI facilitators were also often responsible for much more than just facilitating PPI. Responsibilities included, but were not limited to, recruiting and engaging with public members and Governors; liaising with commissioners, HealthWatch and Government agencies; managing volunteers; compiling reports to Board on patient experience and involvement; handling and reporting on complaints; and managing website content.

These responsibilities likely require a wide-ranging set of skills: analytical, writing, communication, facilitation, and time management skills. The challenges of these roles were evident from PPI facilitators' interviews, and observations of their behaviours during PPI activities (e.g. facilitating a focus group) showed the skills they possessed. PPI facilitators also talked about some specific skills they felt aided them in their roles, such as communication skills and networking. The unique challenges and complexities of PPI facilitators' roles will be returned to in more depth in section 4.9.

Also related to hierarchical structures, PPI facilitators cited the importance of clear Board-level support for and commitment to PPI across the organisation. They cited examples of expressed Board support, such as attendance on committees that involved patients and laypeople. However, they also added that they felt there was limited understanding from Board members of the complexities of PPI and how it should be resourced. As such, they suggested that Board members merely expressing support for PPI was not sufficient, something also found by Anderson et al. (2002). This further demonstrates the tacit knowledge and appreciation PPI facilitators possess that others do not.

Another key point about roles and responsibilities is that these PPI-specific roles tended to be present centrally, in corporate management departments. There were very few examples of PPI-specific roles at service-level. Even when there were individuals whom conducted PPI work at a service-level, their role also included many other activities, such as clinical work. This appeared to be at the root of a debate PPI facilitators and senior managers had (evident mostly in interviews) regarding where PPI should sit within the organisation. Having top-down management of PPI centrally with dedicated resources was perceived to ensure consistency and centralised strategic direction. Whereas having bottom-up PPI work driven by service staff was perceived to likely yield better staff engagement.

A number of PPI facilitators argued that, for PPI to have more impact, there needed to be more staff engagement, involving staff at a service-level. The rationale presented by PPI facilitators was that, as they would be the individuals responsible for delivering improvements on the basis of PPI activities, they needed to be actively involved from the beginning. They reported that a lack of staff engagement was possibly in part due to there being specific named roles centrally in the organisation. Essentially, they were suggesting this gave staff the perception that PPI was someone else's role and that they need not be involved.

In order to discuss the concept of staff engagement and its links to PPI further, it is pertinent here to define staff engagement. The term 'engagement' in the work setting (or more specifically 'attitudinal engagement') has been described as meaning the individual has "a positive, fulfilling, work-related state of mind that is characterised by vigour, dedication and absorption" (Schaufeli et al., 2002: p.74; as cited in Guest, 2015). Engagement of this

type has been linked to higher performance, as individuals are more motivated when they feel actively engaged in their work.

However, in the commercial sector, there is a different type of engagement promoted by consultants – ‘organisational engagement’ (Guest, 2015). The difference between the two distinctions essentially relates to the viewpoint – ‘attitudinal engagement’ refers to how engaged a person is in their own role at an individual level, and ‘organisational engagement’ refers to how well engaged a person is with the organisation that employs them. Whilst there has been a lack of consensus about what organisational engagement is in practice, MacLeod & Clarke (2009) offer the following definition: “a workplace approach designed to ensure that employees are committed to their organisation’s goals and values, motivated to contribute to organisational success, and able at the same time to enhance their own sense of well-being” (p.9).

Using the definitions above, it was unclear whether PPI facilitators were referring to attitudinal engagement or organisational engagement. Their descriptions suggested it was possibly a combination of the two. Given that they perceived staff to be more motivated to implement changes to services from PPI activities if they were actively involved and “owned it” (IA009), this is likely referring to attitudinal engagement. However, other descriptions suggested they were referring to organisational engagement – claims that if staff engaged more in the principles and values of PPI, and saw this as integral to their own role, PPI would have more impact.

4.3.2. Competing priorities and external organisation priorities

Participants indicated that, when there were pressures, some work roles were side-lined to prioritise and manage work more effectively. The accounts from PPI facilitators demonstrated that PPI (that is the active involvement of patients and the public in service developments and reviews), was often side-lined when time pressures required more focus on other important issues, such as complaints. The way professionals expressed themselves during interviews was generally positive about the increases in measuring patient experience and involving them in more diverse activities. However, there was some evidence that patient experience in general, and PPI specifically, were being under-valued by senior management to allow focus on other issues.

For example, formal policies and safety issues often heavily dominated agendas of governance meetings and reports. One might wonder why PPI activities might be side-lined, given that dedicated roles and teams were created to handle that work. In practice, as patient experience and PPI matters were reported to the same committees as numerous other work from other teams (such as safety and risk issues), PPI facilitators essentially had to compete to get their work on the agenda. This is an example of how organisational structures and reporting lines can potentially affect an individuals' or teams' work priorities and, therefore, their individual experiences and feelings about their work.

Competing priorities were from a range of sources; from central Government to local monitoring organisations (such as the commissioners), to internal sources (such as complaints). As such, PPI work appeared to be driven by a wide range of drivers and purposes; some of which were reportedly not clearly defined. Any PPI work that was directly driven by a Government policy or guideline (such as the FFT, NHS Commissioning Board, 2012) was rather strictly defined and monitored, and often featured heavily in reports to Board meetings. Other discretionary and ad-hoc work, such as holding focus groups about specific services; seemed to be less clearly defined and less prominently featured in reports. Interviews and observations showed that a great deal of effort and time (and sometimes considerable finances), went into conducting PPI work that was driven by a Government policy or initiative. Whereas other activities that were driven more by internal sources, appeared to be less well-resourced and frequently side-lined.

Those internal drivers were not necessarily unimportant to the organisation's management, but participants described being drawn to Government policy-driven PPI activities over and above other activities. This seems to be an effect of considerable influence of Government agencies and policies. This is not surprising, given that many Government targets results are published nationally (on the NHS England website for example) and, therefore, every NHS organisation may potentially have their reputation tarnished should poor results occur. As such, any PPI work that was likely to appear in the public domain was seemingly prioritised over other PPI work (this was witnessed in conversations during meetings), despite being perhaps equally, if not more, important. PPI facilitators reported in interviews they felt pressured into focusing on these aspects of their work, preventing them from putting their efforts into what one interviewee described as "developmental" (IC002) work – service improvements etc.

This shows how important protecting their reputation is when it comes to achieving Government targets and policies. In a heavily target-driven and regulated industry, this is not surprising. However, the level of influence of Government targets and policies was somewhat unexpected, as many studies had suggested organisations conduct a wide range of PPI activities, not just those that might be driven by Government policies (Alborz et al., 2002; Crawford et al., 2003; Lowndes et al., 2001a; Milewa et al., 2002). Hands (2013), however, pointed out that the over-prioritisation of protecting reputations and achieving targets is an NHS-wide cultural issue that may even have played some role in the failures of Mid-Staffordshire NHS Foundation Trust (Francis, 2013). As such, the negative influence of this wider NHS culture has potentially been underestimated in PPI literature.

4.3.3. Organisational strategies and PPI drivers

Two of the organisations had PPI-specific strategies and the third had none. Having a PPI-specific strategy in place might be argued to be indicative that the organisation places a high value on PPI work. By this measure, on the surface, it would appear that PPI was valued less in the AHFT than in MHT or SE. However, in both MHT and SE, professionals did not necessarily view having a strategy as a strong enough lever to drive PPI work higher up the agenda. Whilst they reported that having a strategy at all was a positive thing, many were concerned it was not enough to ensure PPI was prioritised and valued across the organisation.

As for individuals in AHFT where there was no strategy at all, the perception appeared to be that having a strategy would significantly improve the focus on and success of PPI. Whether this would have happened is open to debate. Reasons reported for the lack of impact of strategies were that they were in some respects too vague (see example of aim of the strategy in MHT below), and that having a strategy might just be a token gesture by the organisation's senior management to show it supported PPI. PPI facilitators and their colleagues reported feelings of isolation and a lack of direction and cited the lack of organisational direction as a reason for this. These individual perspectives will be returned to in section 4.4.

“Ensure the services and the Trust benefit from the involvement and inclusion of service users and carers.”

Aim of MHT's PPI strategy

The lack of clear PPI strategy (or a strategy at all) suggests that PPI can be difficult to define and plan at an organisational level. This would appear to support general findings about the lack of clear conceptualisations of PPI (Conklin et al., 2012; Mockford et al., 2012; Staniszewska 2008, 2009). It also seemed that the PPI facilitators in these organisations had limited involvement in the production of strategies (both PPI-specific and others such as quality strategies). As the data in this research has shown PPI facilitators appear to have the greatest insights into the complexities of PPI, it seems that their knowledge and expertise may be under-utilised by senior management in planning their organisational strategies. Their lack of involvement in strategic direction might also at least be partly behind their view that the strategy was not clear.

As such, there is a potential disconnect between strategy and PPI delivery, as well as PPI facilitators' roles and tasks. Furthermore, given that PPI is important to a whole range of areas of healthcare service delivery and design, involving PPI facilitators in developing strategies may be something that organisations find beneficial in the future. As Barnes et al. (2006) identified, PPI facilitators can be key allies for patients and the public; therefore, involving PPI facilitators in the strategic direction may serve to considerably increase inclusion of the patient voice in service development. Lightfoot & Sloper (2003) found that, in the case of the involvement of children and young people, PPI activities were generally not driven by PPI strategies in those Trusts that had a strategy in place. The present study supports this finding in that there did indeed appear to be a gap between strategy and delivery. It may be that in Lightfoot & Sloper's (2003) study, PPI facilitators were also not involved in strategy development.

In terms of some of the explicit 'drivers' of PPI, the most frequently referenced purpose was quality improvement, as found in the wider literature (Attree et al. 2010; Milewa et al., 2002; Rowe & Shepherd, 2002). This demonstrated an assumption that, to improve the quality of services, patients' views needed to at least be considered when developing or changing services. PPI facilitators were particularly keen to stress that patients should be actively *involved* in designing services to make them fit for purpose and of a high quality. However, many of the PPI activities did not involve patients in actually designing services. Involvement of patients was usually during the latter phases of service review and redesign, when many decisions had already been made. This supports other studies of PPI (Alborz et

al., 2002; Day, 2008; Rise et al., 2011), that have also found patients are not involved in the early stages.

There are several possible reasons for the lack of involvement of patients at an early stage. Given the multiple competing priorities, staff may set up projects to meet those priorities only to later realise they may need to involve patients and the public. Other projects may initially be deemed to not be appropriate for PPI, particularly if they involve very technical aspects of healthcare – something that both professionals and laypeople acknowledged occurs. There are a number of studies that point out the lack of involvement of patients and the public in technical and specialist areas (Fudge et al., 2008; Franklin & Sloper, 2005). Another reason cited by PPI facilitators is that staff are reluctant to involve patients and the public due to time pressures – their concern is that service improvement and redesign projects will take much longer if they involve patients and the public. This supports research by Crawford et al., 2002.

Furthermore, whilst numerous surveys were conducted by the organisations, there were no examples observed in this study of direct changes because of survey feedback. When professionals were asked about the impact and outcomes of PPI, they mostly cited examples of changes made following formal complaints, or outcomes were minimal such as changes to patient information leaflets (which had often already been designed by professionals). When improvements and changes to services are made following a formal complaint, the patient has had to resort to a severe and negative form of sharing feedback, which may arguably prompt the greatest response from managers to appease the complainant. Outcomes and impact will be returned to in section 4.6.

4.3.4. Organisational culture and ethos

The three case study sites were very different in three ways – size, demographic and geographical coverage, and service type (see section 2.5.2 for detailed descriptions). This was a very deliberate choice of the research study design, to explore commonalities and differences in PPI across different healthcare contexts. There were some explicit references in interviews of organisational culture playing a role in how PPI was done, and observational data also highlighted some differences. These have already been described in section 3.2.2., but by way of a reminder the key differences were as follows: the terms used by staff in each case site varied (MHT staff always used the term “service users”, whereas SE and AHFT

staff tended to use the term “patients”); the variety of methods of PPI also differed in MHT used the widest variety of methods, whilst AHFT tended to favour using surveys, and SE could be placed somewhere in between.

PPI facilitators as well as other professionals in the case sites made suggestions about the impact of organisational culture and ethos. Those in MHT claimed that people working in mental health are generally more comfortable with PPI activities and principles due to “the nature of their work” (IA003), whereas those in AHFT suggested that people working in acute hospitals become too consumed with the fast and transactional nature of their work, resulting in an unease with PPI work. In SE, interviewees (both professionals and laypeople) described how their organisation was freer than NHS trusts and claimed that freedom allowed them to be more innovative and bold in how they conducted PPI activities. (However, it is important to note these were only early perceptions of organisational ethos changes following moving from an NHS trust to a social enterprise).

These differing organisational cultures could be argued to be indicative of a spectrum of approaches to healthcare (and subsequently PPI). On the one hand, in MHT most health professionals spend their days talking and listening to patients (or service users to use their term) in conducting their treatment together (a holistic care model); whereas at the other end of the spectrum, in AHFT, many staff are required to treat patients efficiently and effectively, within a limited amount of time, often with limited involvement of the patient (the medical model). It is important to note here that these are the extreme ends of the spectrum – not all mental health patients will be actively involved in their own care in a holistic care model, and not all acute hospital patients will be treated in the traditional medical model. However, there was evidence (primarily from interviews) of these differing approaches of healthcare delivery either facilitating or inhibiting of PPI work.

One argument made by those in MHT was that professionals who are used to spending time talking with patients for treatment reasons (e.g. talk therapies) have little difficulty in conducting PPI activities, because much of the approach is arguably the same – partnership, patient-centeredness, and equal conversation. Whereas one argument made by some in AHFT was that professionals who are used to the medical model find PPI activities to be challenging, because they do not usually spend extended periods of time talking and listening to patients as one does in PPI activities. Those in SE did not make any such suggestions;

however, from observations, it appeared they operated in a way that would place them around the centre of this spectrum. This supports some earlier work around the conflict between the democratic ideals of partnership and shared decision-making (which are deemed fundamental to PPI), and the traditional and paternalistic approach of the medical model that appears to endure in healthcare (Bury, 2010; Collier & Stickley, 2010). Indeed, Vaismoradi et al. (2015) specifically point out that a healthcare system that is based on patient-centeredness, or the ‘holistic’ model, is needed to facilitate successful PPI.

The evidence here suggests that the paternalistic model is potentially more present in acute healthcare organisations than mental health and community health organisations. This was a rather unexpected finding of the research as, although there are many references to the traditional paternalistic nature of healthcare being in conflict with the democratic ideals of PPI (see sections 1.3.1-5. and 1.4.5.), there is also evidence of the shift away from paternalism (Baggott, 2005; Limentani, 2002; Mold, 2010;). (Though it should also be noted that there is a continuing variation in clinicians’ support of patient engagement, as shown in a recent survey (Sharma et al., 2015.)) It was particularly unexpected that the mental health provider would have a more holistic care culture given the history of mental health provision, which was historically very authoritarian (Borg et al., 2009; Felton & Stickley, 2004).

It is possible that, as mental health provision went through such a significant change in its approach (i.e. the closure of mental health institutions) (Borg et al., 2009; Felton & Stickley, 2004), the shift to the holistic model is perhaps more prevalent than in acute care. In acute care, the approach to care has changed very little – care is still delivered in hospitals in much the same way as in the early years of the NHS. This study shows evidence of a potential key difference between different healthcare providers and their level of probable acceptance of PPI, based on their organisational ethos and culture. However, further research would be needed to compare other mental health and acute healthcare providers to assess this. This will be returned to in section 4.12.4.

4.4. Individual factors

This section discusses factors concerning individuals and their personal characteristics – such as beliefs, motivations, personal skills, and personal barriers. Although the present research focused mainly on organisations and their employees, the research did explore some of the laypersons’ perceptions, such as what motivated them to participate, alongside the personal perspectives of staff. This section discusses both the observed characteristics and self-reported perceptions of the laypeople involved, as well as PPI facilitators and some of their colleagues. The key areas that will be discussed are how the professional characteristics of some laypeople potentially puts them in a position where they are deemed to be ‘unrepresentative’; and the remarkably similar identities and characteristics of laypeople and PPI facilitators.

4.4.1. Too professional to be representative?

As has been described in the Results sections, the patient representatives and laypeople who got involved in the PPI activities observed in these three case sites displayed what might be deemed as ‘professional qualities’. They were (in most cases) articulate, assertive, and capable of contributing to critical debates. Most were also from a professional background (nursing, medicine, teaching, politics, etc.). Furthermore, they were reportedly not just involved in the activities observed, but were also members of multiple other groups, committees, and projects. All the laypeople interviewed described networking behaviours – they would find out about one group or project and subsequently join others through contacts made at each group. This supports findings from several academics (Anton et al., 2007; Barnes et al., 2003; Barnes, 2005; Barnes et al., 2006; Beresford, 2010; Evans et al., 2013; Kearney, 2004; Légaré et al., 2011; Lowndes et al., 2001b; Martin, 2008a; Pickard & Smith, 2001; Rose et al., 2010) – they were essentially part of an ‘in-crowd’ of ‘professional laypeople’. The networking behaviours of these individuals were also not just driven by themselves, but also by PPI facilitators, whom would approach existing groups to recruit participants to new groups and projects. These PPI activities can then become exclusionary to others who wouldn’t learn about them through these networks.

As one PPI facilitator put it, this may mean that they are basically “just another professional at the table” (IA006), rather than a layperson. This issue was something that, interestingly, both professionals and laypeople were wary of. Not only did professionals

suggest it potentially makes them unrepresentative, but some laypeople themselves admitted they did not feel they were very representative, supporting the findings of Martin (2008a). Laypeople claimed they see “the same people all the time” (IB004), and that it would be good to have “fresh blood” (IA007). Given that the laypeople themselves didn’t feel they were representative raises the question of whether professionals should stop engaging with them altogether, or else accept them as another type of professional.

As some studies have suggested, the experiential knowledge of patients and carers should be treated as equal to the technical and clinical knowledge of health professionals (Attree et al., 2010; Bovenkamp & Zuiderent-Jarek, 2013; Bradshaw, 2008; MacDonald & Taylor-Gooby, 2010). Perhaps the role definition of laypeople in PPI activities should be one of “professional patient” (IB004), as one layperson did indeed describe themselves. This would then acknowledge they are not a ‘typical’ patient, but are instead there to offer their own experiential knowledge rather than expecting them to represent the interests of all patients (which is an impossible task in any case).

Indeed, two of the laypeople interviewed, whom had only recently joined their respective PPI activities, described having no guidance or instruction at all from professionals about their role. They reported sometimes feeling unsure about what contribution they could and should make. (The other laypeople interviewed described being unclear about their role at the beginning but had seemingly either developed the role themselves, or had been given guidance later in the process.) This supports findings from other research on the lack of clear definition by professionals on the role of laypeople (Costello & Horne, 2001; Pickard & Smith, 2001). What is unclear is why professionals did not provide laypeople with role definitions – it could be they don’t know themselves and prefer to see the role be defined as the activity develops, or perhaps professionals are not able to agree amongst themselves how to define the role. It seems the debates about representativeness will likely continue if professionals fail to properly define the layperson’s role from the outset.

Furthermore, there were reports from some professionals that laypeople sometimes needed guidance or even formal training (or should have) to be able to contribute confidently to discussions. However, they also acknowledged how this could shift the balance of their role from layperson to expert, as such, rendering them ‘unrepresentative’. This dilemma has been found in the literature – the ‘catch 22’ of needing to offer support to laypeople to enable

them to participate whilst avoiding professionalising them to the point of making them ‘unrepresentative’ (Ives et al., 2012; Learmonth et al., 2008). Professionals may need to accept that laypeople will inevitably become professionalised and frame their role as an ‘expert’ or ‘professional’ patient, rather than expecting them to remain a ‘typical’ patient.

4.4.2. The mirrored characteristics of laypeople and PPI facilitators

One of the most unexpected findings of the present research was how markedly similar the motivations, beliefs and characteristics of PPI facilitators were to the laypeople interviewed and observed. All the laypeople had experienced poor care, discrimination or even abuse (or been close to someone who had); and they claimed to be motivated by wanting to give other people with such experiences a voice where they might not have had before. These beliefs and motivations seemed to be very closely mirrored by the PPI facilitators. This evidence could suggest that PPI facilitators identified themselves as more of an advocate or activist than an employee. It may potentially mean that their allegiance lay closer to patients and the public than to their employer and colleagues. Barnes et al. (2006) found something similar in a study of public participation mechanisms. Some of the officials interviewed (though a smaller number than the present study) had similar activist histories and traits to laypeople, prompting them to conclude professionals’ motivations and backgrounds should be understood as much as the laypersons’.

These findings add nuances to established research on the relationships and interactions between professionals and patients and the public. A large amount of research has examined relationships, in both the contexts of the patients’ own care and in PPI activities (see sections 1.2. and 1.3.). However, what the present research adds to this literature is an examination of the unique relationship between patients and the public, and PPI facilitators, as well as PPI facilitators and their colleagues. Given that PPI facilitators spend a great deal of time attempting to engage with front line staff from very established professions (medics, nurses, etc.), one could argue that it would be very difficult to identify themselves with these individuals, so they instead identify more closely with the laypeople. Indeed, interviews with PPI facilitators provided several accounts of conflicts with front line staff, but not with laypeople.

This can create a considerable power conflict between health professionals and service managers, and PPI facilitators. If health professionals and managers view PPI facilitators as

more closely aligned with patients and the public, there may be conflict. Furthermore, Bolton (2000) suggested that managers may use patient feedback, such as complaints, merely as tools to monitor and performance manage staff, something also suggested about PPI in general by Milewa et al. (2002). If health professionals view PPI facilitators as using PPI to performance manage them, there is also likely to be conflict. PPI facilitators did indeed report resistance from front line staff and service managers when it came to both being involved in PPI work and improving services based on patient feedback. One of the reasons for this resistance may well be how health professionals and managers view PPI facilitators, though this is speculation. This may be something for future research to examine in more detail, as will be discussed in section 4.12.1.

Further adding to these power conflicts was the issue of the creation of an ‘in-crowd’ by PPI facilitators. Due to their shared networking behaviours with the laypeople, there seemed to be an ongoing development of a small group of people PPI facilitators routinely consulted and involved, inviting them to multiple projects and groups. This potentially exacerbates power conflicts with health professionals who may note the small group of individuals PPI facilitators work with, arguing they are unrepresentative in order to reject recommendations of PPI facilitators for service change.

Another way in which laypeople and PPI facilitators were similar was in how they defined their own role. As already described, they all seemed to be motivated by experiences of, or witnessing, poor care, discrimination or injustice. As such, they identified themselves as advocates wanting to speak out for others who may have experienced similar issues. This confirms findings from existing literature (Anderson et al., 2006; Barnes et al., 2006; Cotterell et al., 2010; Donaldson et al., 2007; Freitas, 2015; Lowndes et al., 2001a, 2001b; Rutter et al., 2004) on motivations and identity perspectives of laypeople. The present study adds to the literature by identifying these same motivations and identity perspectives are present in professionals, but particular PPI facilitators. Interestingly, there was nothing in the data suggesting that any laypeople identified themselves as citizens carrying out civic duties, though there were occasional references to this by professionals (e.g. “those that would come along anyway because of their civic civil type thing” (IA006)).

Many individual factors appeared to play a role in PPI, particularly considering the emotional labour PPI appeared to involve. As can be seen from the data, PPI facilitators,

many of their colleagues, and laypeople were passionate and highly committed individuals, keen to do ‘right’ by the wider public and for healthcare services. This demonstrates how key identity and motivation issues are in defining how PPI works, especially given that PPI is an inherently social process. What has been particularly important in this research is seeing these individuals in their contextual environments – they can be constrained, and sometimes even demotivated, by structures and hierarchies, and strategies and policies. Indeed, many of the constraints that PPI facilitators said needed to be resolved involved some change to organisational factors – more support from senior management and the Board for example.

4.4.3. Personal definitions and conceptualisations of PPI

Another key finding was the lack of clear definition and conceptualisation offered by all participants. Vague and abstract terms were used to describe how they defined PPI (see section 3.4.1.3.). This is something not explicitly explored in the literature, but which further adds to a large quantity of literature on the lack of clear and consistent conceptualisation of PPI (see section 1.6.5.). The definitions offered by participants seemed to primarily focus on methods rather than other elements of PPI, such as role definitions. This may demonstrate the disconnect Frith et al. (2014) describe between theory and practice in that practitioners do not define PPI in the same way as academics, as practitioners’ primary focus is on the practical elements of PPI.

Further evidence of this was in the apparent overlap and conflict between ‘patient experience’ and ‘patient involvement’. Although PPI facilitators made some distinction between the two concepts, as the literature does, most people seemed to view patient experience as part of PPI – specifically that measuring patient experience is a set of methods of PPI (e.g. patient surveys, formal complaints, etc.). As already discussed in section 4.3.2., corporate reports often contained more information on patient experience figures (e.g. results of surveys) than PPI projects, as there was reportedly greater pressure from Board members and senior managers to focus on numbers and data. This led to frustrations reported by PPI facilitators that they couldn’t focus on work that reportedly really motivated them – developmental project work to improve services. This tension will be returned to in section 4.7.3.

4.5. Logistical and practical factors

This section discusses the logistical and practical factors involved in PPI activities – i.e. the where, when, and how. Many of the findings here confirm what the wider research has already concluded (see sections 1.4.1-6). However, a key addition to make here is to consider how PPI facilitators navigate some of these practical factors. Some might argue that practical barriers are used by professionals to oppress the patient and public voice. The current research adds to this by putting forward the additional and contrasting perspective of PPI facilitators. A key part their role was reported to be to remove, or at least limit, the practical barriers. Therefore, the evidence suggests there is limited opportunity for healthcare professionals and service managers to use practical barriers as reasons for blocking or undervaluing PPI.

As this research takes a pragmatist perspective, paying due attention to the logistical and practical factors in PPI was a key objective of the research. Deciding what methods of PPI to use, where to hold the activity, what day and time to conduct it, and how to recruit participants were found to be considerable challenges for PPI facilitators. It was clear that, regardless of when, where, and how the PPI activity was conducted, some members of the public and patients were going to be excluded. PPI facilitators described it as being very challenging to always provide inclusive PPI activities because it is impossible to cater for everyone. In reality, methods had to be adapted based on the target audience and purpose of the specific PPI activity. Sometimes, even when alternative arrangements were made to attempt to make the activity more accessible, these adaptations were not always successful.

4.5.1. PPI methods

A range of PPI methods were observed in the present research and can be broadly categorised in the same manner as research methods – quantitative and qualitative; an observation that Munro (2008) also made. Quantitative methods consisted of surveys and questionnaires, whilst qualitative methods consisted of focus groups, consultation events, and committees and panels. The methods chosen were reportedly broadly determined by the purpose of the activity. For example, in AHFT, managers were concerned about why their scores in the National Cancer Survey (see <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey> for more information) had reduced, and as such, they wanted to review the chemotherapy service with existing patients. PPI facilitators chose to

conduct a focus group to gather detailed information about their experiences of chemotherapy and identify actions that would improve the service.

Unlike methods used in academic research, however, these methods had not gone through any rigorous design and testing processes before being employed. In social sciences research, a survey would have to be tested for its validity and reliability (for example to ensure questions are not too leading), but no such tests were done before using them as PPI methods. This could be explained by two reasons: a lack of research training amongst PPI facilitators and managers, and a lack of available time to robustly design and test out methods. Furthermore, when a PPI activity was determined by a Government target or initiative, the methods were already designed and there was limited flexibility. As such, one could argue that the lack of strong robustness and validity of these methods may lead to erroneous interpretations of patients' wishes and low impact service improvements.

In some PPI activities, there wasn't a clear reason why the method was chosen and it sometimes appeared to be more to do with prior existing arrangements being continued. For example, in SE, their Patient Experience Group had evolved from another group when the organisation was a PCT. The PPI facilitator explained they had asked the members if they wanted to continue meeting as a group once they became a social enterprise and the majority had agreed. One might argue that, in instances like this, the decision to continue with these activities might not simply be based on motivation to involve patients and the public but could also be about avoiding conflict and damaging existing relationships. Another rationale for continuing with the specific activity, even after largescale organisational change, could be for convenience and consistency. Furthermore, where an activity continued long-term, the purpose of the activity was not clear and sometimes it even appeared to drift along rather aimlessly. This contrasts with one-off activities like focus groups where the purpose was generally set out more clearly from the beginning.

Interestingly, some PPI facilitators argued that the one-off and focused PPI activities had more obvious impact than wider and long-term methods because the process could be clearly tracked from the beginning to the end output (e.g. a decision regarding how a service was delivered). For example, in MHT, a consultation regarding proposed changes to a service (specifically the proposed removal of an "expensive" (IC002) clinician) resulted in a change to that decision in that a compromise arrangement was made because patients were so

strongly opposed to the proposal. In this example, there was a clear purpose from the beginning, and a subsequent clear link between what patients said they wanted and the final outcome. The impact of PPI will be returned to in section 4.6.

4.5.2. Logistics – does the where and when suit us or them?

A considerable challenge for PPI facilitators was reportedly when and where to hold PPI activities. They reported being aware that some venues and times of day would not suit certain people. Conducting an activity on a week day between working hours, for example, means people who work full time will not be able to attend (or would have difficulty attending). Regardless of where or when an activity was held, there were always downsides. Where activities were held outside working hours and in venues other than their own facilities, there was a considerably higher financial cost compared with activities conducted during working hours in their own facilities. As such, there was a tendency of PPI facilitators to, in practice, conduct activities in the latter manner, whilst simultaneously acknowledging these methods would exclude some sections of society. These practical and logistical barriers are well referenced in the literature (see section 1.4.4.).

PPI facilitators reported having to face difficult decisions about getting greater inclusive engagement whilst simultaneously keeping costs down. Clearly many PPI methods will be inaccessible to some groups. Some research has suggested that professionals do not limit or remove these barriers enough, and as such, PPI actively excludes certain individuals (see sections 1.3.4. and 1.4.6.). However, the present research showed that PPI facilitators do make attempts to make activities as accessible as possible, such as changing the venue, the time of day, and offering repeated times (in both SE and AHFT, a series of focus groups were attempted several times due to poor attendance). This demonstrates a willingness on their part to make PPI more accessible, but practical factors still inhibited much of their efforts.

PPI facilitators reported being continuously frustrated by the lack of engagement from minority groups and were acutely aware that many activities were not accessible enough to these groups. Unfortunately, the multiple organisational barriers (such as a lack of financial resources) meant that many barriers for individuals could not be totally removed or limited by PPI facilitators. As this research comes partly from a pragmatist perspective, the argument here is that organisational barriers restrain PPI facilitators so much so that barriers for individuals participating are commonplace and sometimes unavoidable. Some might argue

that professionals put in place barriers to participation, consciously or not, as a way of exerting authority; but the present study data suggested PPI facilitators are seemingly presented with as many barriers as the laypeople. As such, senior management may need to remove or limit the barriers PPI facilitators face in making PPI activities accessible. Further discussion of the recommendations for practitioners will be returned to in section 4.12.2.

4.5.3. Recruitment methods – active exclusion?

Before PPI activities can start, there is of course a need to recruit participants. The present research found that the nature of the PPI activity was connected to the method of recruitment. Where the purpose of the activity was to engage a specific patient group, PPI facilitators would contact existing patients. However, most PPI activities that were observed were not of this nature. When laypeople were asked how they got involved, all reported finding out about the activity through other groups and networks, and PPI facilitators explained that they utilised existing networks (e.g. public membership).

Interestingly, although PPI facilitators had acknowledged that some methods of PPI and the logistical factors would regrettably exclude some individuals, they did not seem to make the same conclusion about their recruitment methods. This means they had either not considered that this limited method of recruitment would exclude certain people, or they had considered it and neglected to mention it. Again, it is possible that PPI facilitators felt compelled to use these networking methods of recruiting to save time and effort due to pressures they faced from several other factors (such as the competing priorities discussed in section 4.3.2.).

PPI facilitators described their methods for recruiting participants in very pragmatic terms, such as claiming that representatives from existing networks are already well equipped and confident in PPI. There were also references to the wishes to partner with other organisations locally because they were likely to be consulting the same patients and public members. There was no acknowledgement from any professional interviewed that by recruiting from already established contacts and networks, they were in effect excluding others. Although one professional did remark that she would “see the same faces” (IA008) at multiple events and forums, there was still no reference to the potentially exclusionary nature of this practice. As already stated, they are either unaware it has exclusionary implications, or they are aware it excludes, but choose to continue for practical reasons. Their descriptions

were certainly very pragmatic in nature, so one might deduce they are pressured more by practical realities than by the need to be inclusive (if they perceive that pressure at all).

4.6. Outcomes & Impact

‘Outcomes’ here means actions that reportedly happened following on from a PPI activity, i.e. an end product (most ‘outcomes’ were reported during interviews as they were unobservable given that they happened after the PPI process being observed). ‘Impact’ here refers to changes in culture and attitude, and largescale organisational change. A systematic review by Conklin et al. (2012) identified that many studies, whilst they do not clearly define outcomes and impact, generally look for the (perceived) impact on power sharing by laypeople and shared decision making in outcomes or actions. As this study did not focus solely on perceptions of impact and outcomes by laypeople, broad definitions have been used to allow for differing views on outcomes and impacts by multiple stakeholders. Interviewees were not presented with a definition of outcomes or impact when being asked their views to allow for freedom of expression of ideas. Any reports of outcomes were also noted during observations.

4.6.1. Outcomes

Some professionals were able to give examples of changes to services as a result of PPI activities; many of which were very simple, and what might be called ‘quick fixes’. Examples included amending patient information and signage, installing equipment to aid access (e.g. intercom systems), and changing the days and times clinics are held. Simple solutions like these were common outcomes and represent a willingness by management to act on patient feedback. However, more complex issues fed back by patients and carers (such as poor communication by front line staff) did not appear to result in any reported or observed outcomes. Indeed, there were often heated debates during meetings about how to change behaviours and culture. These issues require much more complex solutions (if there is a solution at all), and they are often linked to embedded cultures. Achieving culture change in the health service is very difficult and can take many years given how multi-faceted it is (Scott et al., 2003).

Several reported outcomes and planned outcomes related to staff training. During PPI activities and at meetings, senior managers would often answer a problem from a patient by saying they would update staff training. As already described, this may suggest an inherent assumption that improving a patient’s experience is all about staff training, squarely putting the blame on staff. This may be evidence of what Bolton (2002) described as a system of

monitoring and performance managing of staff rather than actual quality improvement initiatives. However, it is also worth noting it was PPI facilitators whom were generally responsible for making recommendations based on patient feedback and, as their role was not to line manage front-line staff or service managers, it is potentially unlikely that it was used as a management tool. Of course, those whom manage PPI facilitators may well have deemed PPI to be a way of performance managing front-line staff at arm's length, but this is difficult to assess given that few senior managers were interviewed. Again, this may be something for further in-depth research to assess.

Despite these examples, professionals gave imprecise answers in how they termed impact or outcomes. This appears to be the inherent problem with research that tries to identify and assess the impact of PPI – if the practitioners involved are unclear, research studies will continue to have difficulty evidencing impact, as Conklin et al., (2012) have found. Furthermore, what one practitioner may deem to be a successful outcome of PPI may differ considerably from another practitioner's viewpoint. Likewise, laypeople may have a variety of views on what successful outcomes of PPI are.

There are a number of possible reasons for a lack of clear impact from PPI activities. One reason may be that there is a lack of defined process internally for PPI activities through to the desired end-point – often activities reportedly began with a lack of clarity about their purpose and intended outcomes. More formal mechanisms such as complaints and consultations tend to have a more clearly set out purpose and process. As such, it may be that participants are more easily able to recall these instances because they were clearly set out. Other methods such as focus groups and surveys do not necessarily have a clearly set out end-point or purpose.

4.6.2. Organisational and cultural impact

In this research, there was no clear evidence from interviews, observations, or document reviews that PPI resulted in any significant changes to organisational policies and strategies. However, in terms of the wider impact of PPI, there were some suggestions from professionals that the increases in PPI activities, and the increased attention on patient experience measures, was changing attitudes amongst staff. This has been found elsewhere (Crawford et al., 2002; Lightfoot & Sloper, 2003; Mockford et al., 2012). There were reports

from PPI facilitators that more staff were coming to them wanting to learn about patient experience and how they could involve patients in improving their service.

Whilst the timeframes of the PhD did not allow for assessment of the long-term impact of PPI on organisational attitudes and culture, these perceptions point to a potentially changing culture around PPI in healthcare. Healthcare has historically been paternalistic and sometimes even oppressive in its practices (Baggott, 2005; Borg et al., 2009; Felton & Stickley, 2004; Mold, 2010), whereas now policies at both the national and organisational levels demonstrate a continuing shift from paternalism to partnership between patients and the public, and healthcare professionals.

4.6.3. Does PPI have negative outcomes and effects?

Staniszewska (2009) pointed out the lack of literature on the potential negative effects and outcomes of PPI. Whilst the present research did not set out with exploring this as an explicit aim, there were some potential negatives reported by individuals. The most notable reported negative effect of PPI was the potential for it to lead to unrealistically raised expectations, as described in section 4.2.2. This is a particularly important effect given the significantly increasing demands on the NHS, which have reached a “humanitarian crisis” level, according to the British Red Cross (Campbell et al., 2017). Other than the potential to raise expectations, no other negative effects of PPI were reported or observed. There may well be further negative effects, but given that the individuals interviewed and observed were generally very positive about PPI, they may have been reluctant to suggest any significant negatives, or perceived there to be no other negative effects.

Another factor not reported widely in the literature is that of ‘costs’ of PPI work (Mockford et al., 2012; Pizzo et al., 2014). Again, this study did not set out to explicitly examine the costs of PPI work, but many participants did report there being considerable resources required, both financially and with regards to staffing. They claimed these costs were largely unmet by their organisation and the phrase “beg, borrow and steal” (IA009) by one participant summed up the difficulty PPI facilitators had in resourcing their work. Clearly PPI facilitators viewed resourcing to be inadequate, but this is the perspective of a group of individuals who repeatedly reported wanting to do more in-depth PPI work.

As such, there is potentially a disconnect between how senior management (e.g. Board members) quantify the value of PPI work, and how PPI facilitators value it. Either senior management deem it to be adequate to conduct only basic PPI work, or they do not have the same deep appreciation for the breadth and depth of PPI work as PPI facilitators do; and therefore, do not resource it significantly. However, given the considerable financial pressures the NHS has been under, it is equally likely to be a case of there not being enough money in the system, rather than a lack of senior management support of PPI. Another possible reason for an apparent lack of resourcing may be that senior managers in organisations want to simply demonstrate they are doing something. This might again explain the disconnect PPI facilitators' perceptions of what PPI work entails, and the financial and physical resources attached to it.

4.7. Three tensions in PPI work

Throughout the analysis process, it became apparent that there seems to be three ongoing tensions in PPI work, which were particularly challenging for facilitators to balance. These were key issues that seem to apply to most, if not all, areas of PPI work. These tensions were:

- Top-down versus bottom-up management
- Individual versus collective needs
- Patient experience versus patient involvement

4.7.1. Top-down versus bottom-up management

In interviews with professionals (and some laypeople), there were suggestions that PPI works best when it is delivered and acted on with or by front line staff and service managers. This is similar to findings that PPI works best at a ‘grass roots’ level (Attree et al., 2010; Barnes et al., 2004; Barnes, 2005; McEvoy et al., 2008). Indeed, all PPI facilitators suggested there needed to be more front-line staff engagement to improve the success of PPI initiatives and projects. However, what these professionals also suggested was that they felt they had to conduct the work themselves because there were more barriers for front line staff (e.g. time resources) than they themselves had. There was also a debate raised by some that the lack of engagement of front-line staff is potentially partly because of ‘labelling’ corporate roles as being responsible for PPI – they argued this encourages staff to disengage because they believe it’s somebody else’s role. This is something Fudge et al. (2008) also identified as an issue in their study of stroke care improvement projects.

As such, there was an on-going tension between the pros and cons of conducting PPI centrally (top-down, or ‘centralisation’) and locally (bottom-up, or ‘decentralisation’). PPI facilitators were, as result, frustrated by their continued efforts to engage front-line staff and finding they needed to intervene more than they would ideally like because, as they saw it, PPI works best when there is a bottom-up approach. In theory at least, decentralisation should motivate front-line staff to take on these responsibilities and engage effectively in the process by giving them greater autonomy. However, Hales (1999; as cited in Brooks, 2009) points out that decentralisation is not enough to motivate individuals and change their behaviours. Other management techniques and approaches are needed (e.g. appraisal systems). As such,

the pros and cons described by PPI facilitators support the wider management literature. An analogy from Cowden and Singh (2007), though originally referring to Government bodies, encapsulates the tension of top-down versus bottom-up management:

“[Their] position is analogous to a frustrated parent who is desperate for their children to go to sleep without further intervention but keeps finding themselves having to adopt more and more authoritarian strategies to deal with their unruliness.” (p.14).

4.7.2. Individual versus collective needs

Throughout this research, there was also an ongoing tension between individual and societal needs, or what some might call personal needs versus ‘the greater good’. As already discussed, the issue of representativeness was clearly a concern for many professionals, including the PPI facilitators themselves. Most professionals interviewed and observed were wary of ‘personal agendas’ from individual laypeople; and there were instances where chairs of committees and groups had to close down any contributions that veered too closely into personal complaint stories, as described in section 3.3.1.2. The discussions in PPI activities and the accounts from professionals suggested that, whilst personal stories are valued in terms of adding contributions to a discussion, they have the potential to detract from ‘the bigger picture’.

Large public service organisations, such as these case sites were, must constantly make decisions about how to run their services to the highest possible standards; whilst simultaneously managing increasingly tight budgets. Therefore, inevitably, difficult decisions must be made that would have a detrimental effect on some patients, but that could yield a considerable benefit to other patients. For example, if a small clinic is poorly attended, it may be subject to closure, allowing funds to be moved to another service with perhaps a much higher demand. Due to this tension, PPI facilitators have a considerably challenging role in giving individuals an effective say, since they are just that – individuals, with their own personal views, beliefs, and experiences. These individuals’ wishes may be at odds with the priorities and capabilities of the wider organisation, presenting PPI facilitators with a significant conflict to manage. This comes back to the issue of raising expectations – by involving patients and the public, the expectation of those individuals will be that their experiences and wishes are important enough to be of use to the organisation.

In reality, it may be that those wishes and experiences do not match the organisations' priorities, and are therefore, of little or no value. Furthermore, although the literature highlights that patients possess something professionals do not – experiential knowledge – it appears that this does not necessarily place patients in a position of influence over decision-making, particularly if that knowledge conflicts with wider organisational priorities. This is not to say patient perspectives are not valued at the individual level, but are instead not always valued at the organisational level. This adds to findings from Croft et al. (2016) regarding managerial dominance over decision-making and patients' views being marginalised because of their conflict with organisational priorities.

These findings build upon similar findings to those of Renedo & Marston (2015a) whom found that collective and individual notions of quality improvement were conceptualised by patient participants. They simultaneously described quality improvement as being dependent on collective action – multidisciplinary teams working together with patients – whilst also describing the importance of self-improvement on the part of patients (i.e. improving their own health by changing behaviours and attitudes). Renedo & Marston's (2015a) study is particularly intriguing in that patients themselves highlighted the conflicts between individual and collective needs, which indeed does mirror the perceptions of various participants in the present study – both professionals and laypeople.

4.7.3. Patient experience versus patient involvement

This tension refers to the issue of interchangeable terms and the confusion this creates about the purpose and conduct of an activity. Returning to Arnstein's (1969) ladder of participation, PPI methods can easily be categorised into levels of involvement, with providing information to patients and laypeople at the bottom, and co-design and co-delivery of services at the top. PPI facilitators were clearly keen to have more of a variety of methods of involvement, citing that conducting surveys is not true involvement and is simply more of a measure of patient experience. However, PPI facilitators often resorted to conducting simple surveys and small focus groups for a whole variety of reasons (such as resources and competing priorities, as already described in depth in the results sections).

PPI facilitators also often reported feeling that managers and front-line staff, as well as Board members, did not really appreciate the breadth of PPI activities and their purposes. This is potentially because other staff in organisations do not have the same deep

understanding of PPI as facilitators do. This may be, at least in part, due to PPI facilitators' 'closeness' to and tacit knowledge of PPI in practice. Interestingly, PPI facilitators did not suggest any specific measures on how they might be able to put more focus on in-depth and targeted PPI, and instead put forward more general practical suggestions for improvements, such as ring-fencing budgets.

In AHFT, one of the PPI facilitators expressed concern that 'patient experience' rather than what they deemed to be "true" (IC002) involvement often took precedence because the Board reportedly wanted to see high-level numbers (e.g. percentage who were happy with the service and numbers of complaints). Some PPI facilitators reported being frustrated by front line staff conducting surveys and referring to this as 'patient involvement', when they instead viewed it as a basic measure of patient experience. In essence, PPI facilitators seemed to place PPI methods in a hierarchy much like Arnstein's (1969) ladder of participation. They seemed to view surveys as a 'lower rung' on the ladder and aspire to achieve more involvement of patients and the public in co-design and co-delivery of services, sharing power in decision-making in the organisation. Perhaps front-line staff and Board members do not share the same views of PPI methods, perhaps due to their distance from practice. It is important to note that there is a large body of research on 'patient experience', which hasn't been reviewed here, but it is worth noting that patient experience as a concept has been as poorly defined as PPI (Rowland et al., 2017); the present study confirms the lack of conceptual definition and blurring of concepts in practice.

Research (e.g. Fumagalli et al., 2015) has shown how interchangeable terms in PPI work can cause confusion, and how one person labels an activity can have very different meanings for someone else. PPI facilitators seemed to suggest that they had a greater and more in-depth understanding of PPI and its range of methods than other professionals, perhaps because of their day-to-day connection with it and the mediating role they have between multiple stakeholders. They were fully versed in the barriers and facilitating factors, and presented clear and rational arguments about what they view as true patient involvement. Their dilemma seemed to be how to get others to understand PPI in the same terms they did. Of even greater challenge, getting Board members to understand it in the same terms was something PPI facilitators also wanted to achieve.

4.8. Constructing a conceptual framework

One of the main aims of this study was to develop a conceptual framework to demonstrate the multifaceted nature of PPI and the multiple factors that influence its conduct and impact. PPI is a complex social process seemingly influenced by a plethora of factors at the societal, organisational, and individual levels. The following conceptual framework presented attempts to show how these factors interact at the micro level (Figures 23-28). The framework was developed throughout the process of data analysis – potential relationships between factors were identified and added to the framework in an iterative process.

Due to the complexities identified in the data, it was not possible to present the conceptual framework in one figure. As such, the series of figures that follow present various elements of the framework: how factors interact within their groups, how factors interact with factors in other groups, and which factors appear to lead to particular outcomes and impacts. The first diagrams below (Figures 23-26) show how the various groups of factors interact within their groups.

Key to all diagrams below:

TEXT IN CAPITALS = findings that are new or add nuances to existing literature

-----> = factors that decrease or inhibit the second factor

—————> = factors that increase or facilitate the second factor

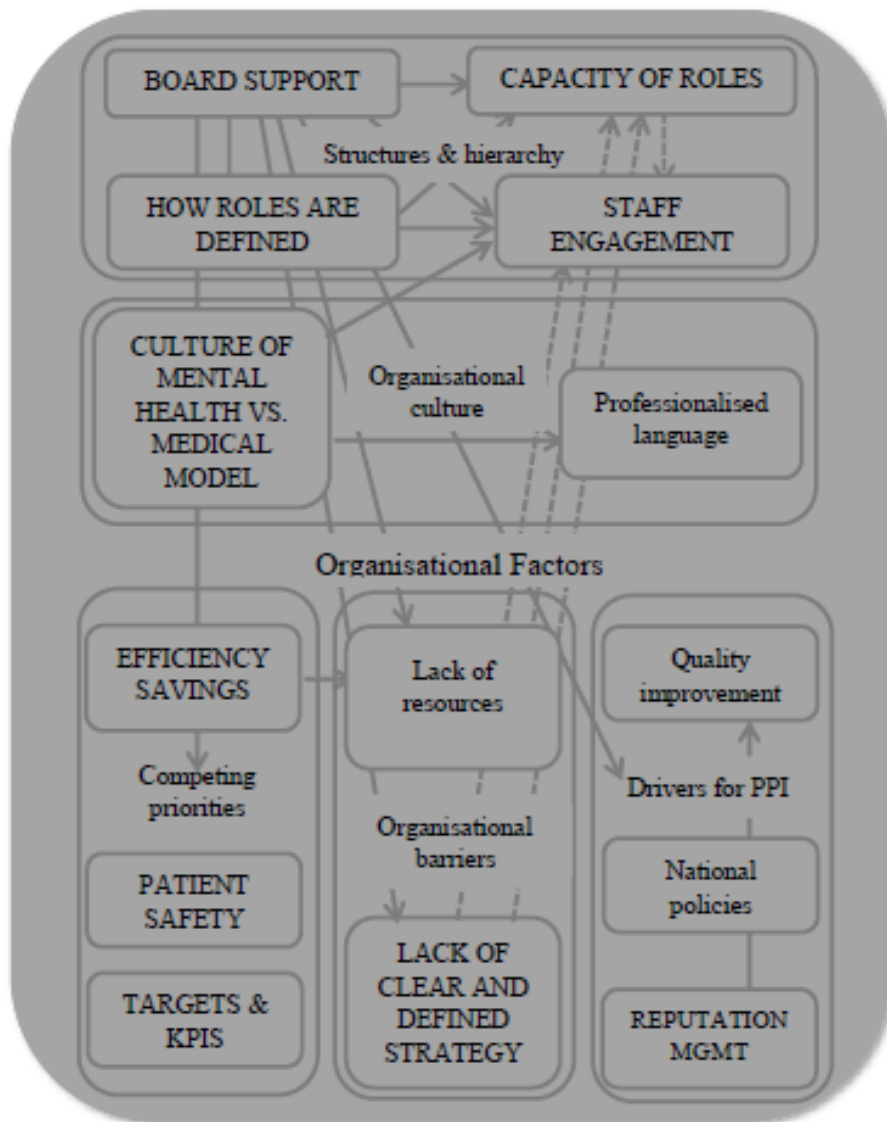
Under Political & Societal Factors (see Figure 23), the rise of social media and digital technology appears to be contributing to the ongoing rise of consumerism already discussed in section 4.2.2. The rise of consumerism is also likely contributing to the concept of ‘survey fatigue’ – the notion that consumers are becoming tired of multiple service organisations requesting their feedback, and that this in turn leads to ‘unrepresentative’ voices. Furthermore, the marginalisation of particular sections of society further contributes to unrepresentativeness.

Figure 23: Internal factor relationships – Political & Societal Factors



Under Organisational Factors (see Figure 24), a wide range of interactions were noted in the data. Board-level support for PPI contributed to numerous other factors – structural and hierarchical factors, competing priorities, drivers for PPI, and organisational barriers. How roles are defined unsurprisingly influenced staff engagement and capacity of roles (particularly the roles of PPI facilitators). In addition, organisational culture (mental health versus medical model) appeared to influence professionalised language (more medical terminology is associated with the medical model) and staff engagement (staff working in mental health seemed more at ease with PPI work). The competing priority of efficiency savings unsurprisingly contributed to a lack of resources being available for PPI work, and in turn, that lack of resources limited the capacity of roles (particularly PPI facilitators). The lack of clear and defined PPI strategy also added to limiting the capacity of roles. Finally, the need to maintain the organisation’s reputation contributed to the driver for PPI of quality improvement.

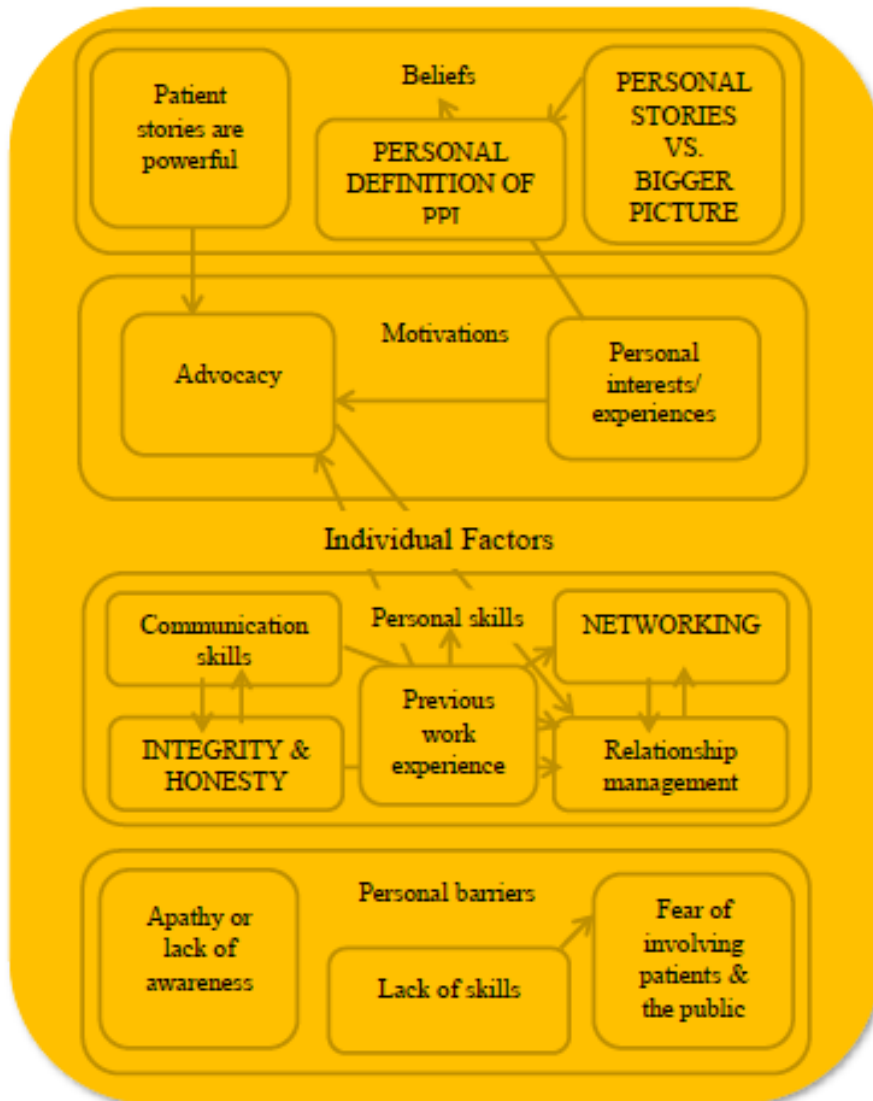
Figure 24: Internal factor relationships – Organisational Factors



Data also indicated there were numerous interactions between Individual Factors (see Figure 25). Personal experiences and interests appeared to influence people’s beliefs, and in turn, the belief that patient stories are powerful seemed to contribute to the motivation to advocate for others. Furthermore, particular personal experiences also seemed to directly motivate people to be advocates (e.g. laypeople with experiences as a patient receiving poor care). Those with strong motivation to be advocates appeared to be more likely to work hard in maintaining relationships. Previous work experience appeared to contribute to their personal skills and their motivation to advocate for people (if a person had witnessed poor treatment of a particular group of people in their previous work for example). There appeared to be a two-way relationship between communication and integrity and honesty, and

networking and relationship management. In addition, having integrity and being honest seemed to be important for maintaining relationships. Finally, having a lack of skills for PPI work appeared to lead to an increased fear of involving patients and the public in service developments.

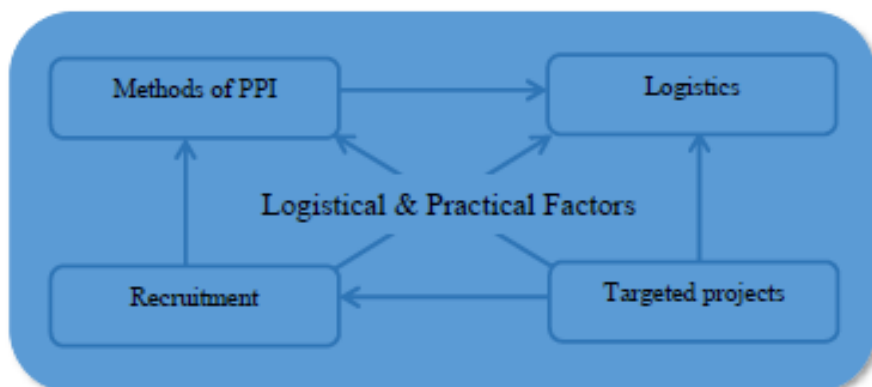
Figure 25: Internal factor relationships – Individual Factors



There were also some interactions between Logistical & Practical Factors (see Figure 26) – the methods of PPI chosen unsurprisingly appeared to influence logistics (e.g. where and when PPI activities were held). Conducting targeted PPI work influenced logistical arrangements, how participants were recruited, and what methods of PPI were used. The

people recruited for the activity also influenced the chosen methods and logistical arrangements (e.g. venues with increased disabled access).

Figure 26: Internal factor relationships – Logistical & Practical Factors



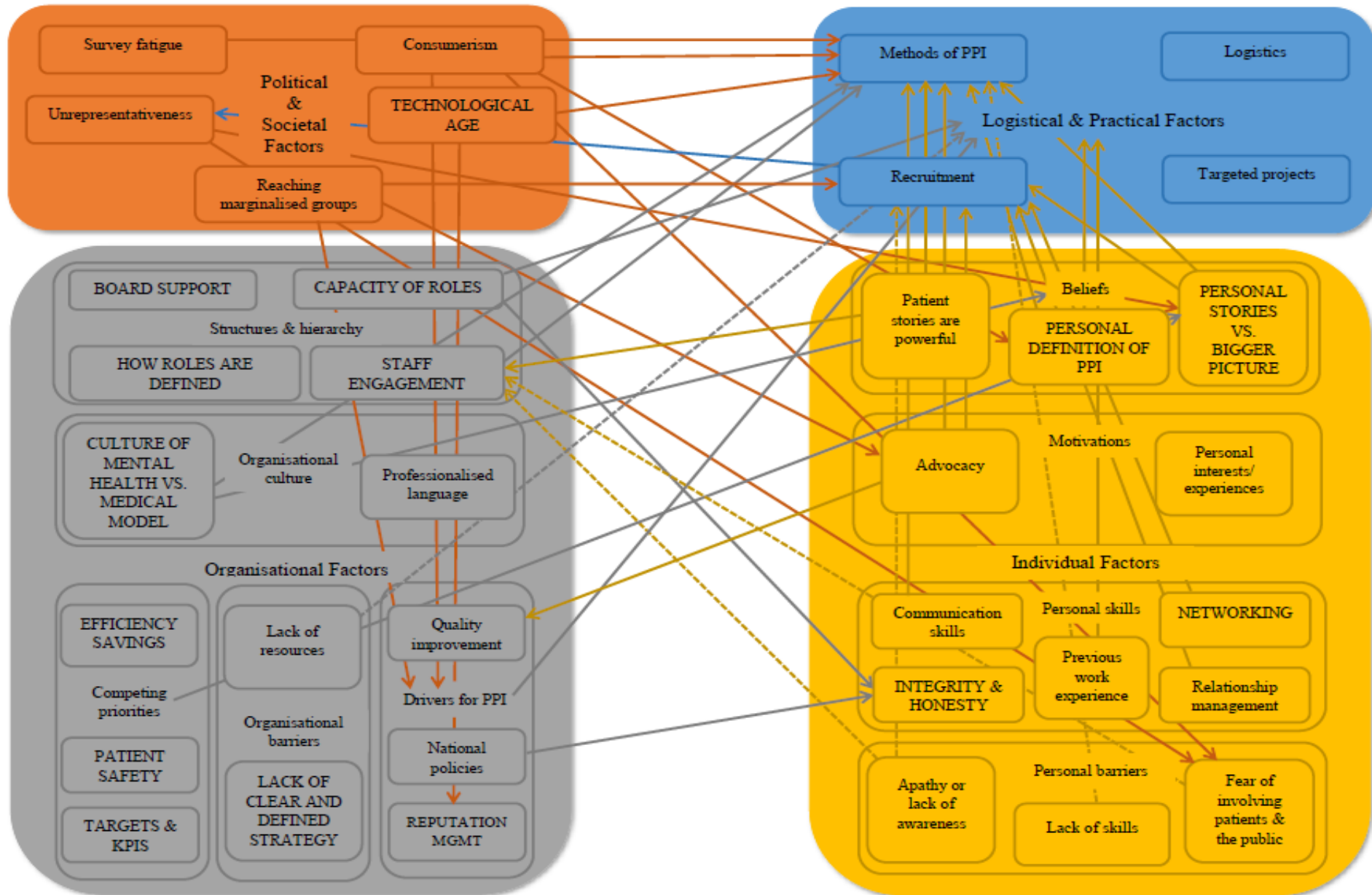
The next diagram (Figure 27) shows how factors interact with factors in other groups. This shows clear visual representation of how complex PPI in healthcare organisations can be, and how wide-ranging the influential, facilitative and inhibitive factors are. To aid interpreting the diagram, given how complex it is, the table below (Table 19) summarises each factor and the factor/s it influences, facilitates or inhibits.

Table 19: Summary of externally influencing factors

Factor name	Factor group	Factor/s influenced
Survey fatigue	Political & Societal Factors	Methods of PPI
Consumerism		Drivers for PPI
		Personal definition of PPI
		Fear of involving patient and the public (because of increasing expectations)
Technological age		Methods of PPI (e.g. using online surveys)
		Reputation management (due to exposure through social media)
Marginalised groups		Advocacy
		Drivers for PPI
Unrepresentativeness		Personal stories vs. bigger picture
		Fear of involving patients and the public (fear of the ‘usual suspects’)

Capacity of roles	Organisational Factors	Logistical & Practical Factors
		Integrity & honesty (how much information staff can divulge)
Staff engagement		Methods of PPI (designing methods to get staff engagement as well as layperson involvement)
Culture of mental health vs. medical model		Methods of PPI (greater active involvement and co-design in mental health culture)
		Beliefs
Competing priorities		Personal stories vs. bigger picture
Lack of resources		Logistical & Practical Factors (e.g. costs of venues)
National policies	Integrity & honesty (being honest about remit of PPI in context of national policies that are fixed)	
Methods of recruitment	Logistical & Practical Factors	Unrepresentativeness
Patient stories are powerful	Individual Factors	Methods of PPI (e.g. having patient stories at Board meetings)
		Staff engagement (greater staff engagement due to emotive nature of stories)
Advocacy		Methods of PPI
		Methods of recruitment
		Quality improvement
Beliefs		Logistical & Practical Factors
Personal stories vs. bigger picture		Methods of PPI
		Methods of recruitment
Networking		Methods of recruitment
Relationship mgmt.		Methods of recruitment
Communication skills		Methods of PPI
Apathy/lack of awareness		Methods of recruitment
Fear of involving patients/the public		Staff engagement (staff engagement less likely from staff who fear PPI)
Lack of skills	Methods of PPI (lack of skills of facilitator/s limits effectiveness of methods)	

Figure 27: External relationships

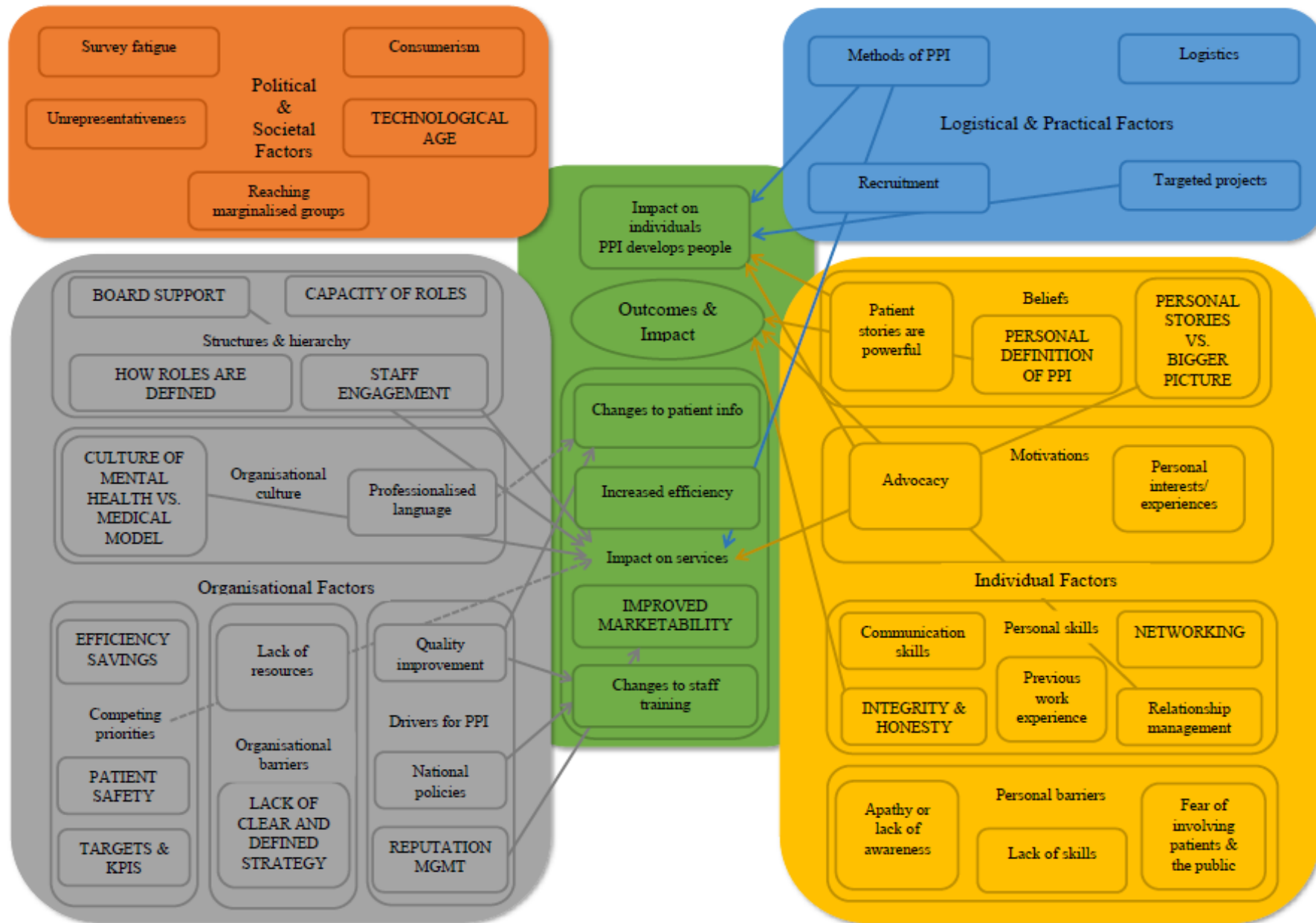


The final diagram of the conceptual framework (Figure 28) illustrates which factors appear to influence or lead to outcomes and impact. Some factors only seemed to impact the individual – methods of PPI (such as co-design), targeted PPI projects (i.e. with specific individuals), and the motivation to advocate and the belief that patient stories are powerful, all seemed to improve the layperson’s self-esteem and confidence. The belief in the value of patient stories also seemed to impact on staff development. The methods of PPI chosen also seemed to impact on service outcomes – for example, because MHT had done a consultation that formally sought patients’ views, a compromise was made in response to that feedback.

The issue of the tension between personal stories and the bigger picture had an influence over what outcomes there were for services. Competing priorities had a considerable influence on outcomes. For example, in SE, the refurbishment of a clinic facility had involved seeking patient feedback, but feedback on the type of flooring was ignored by decision-makers, whom reportedly chose instead a cheaper option to save money. Board support and staff engagement were also important influencing factors for outcomes – certain decisions for service change needed the support of the Board, and likewise, even when a change is introduced, its success and sustainability depend heavily on good staff engagement. Organisational culture also appeared to impact on the acceptability of putting service change in place – the medical model that does not encourage partnership working means that patient views can be marginalised in favour of staff ‘expert’ views (discussed in section 4.3.4.). In addition, where there was greater professionalised language, changes to patient information as a specific outcome were limited.

In terms of drivers for PPI, quality improvement seemed to drive changes to staff training, in that there appeared to be a fundamental assumption that quality improvement could only occur if staff changed their behaviours (see section 4.12.3. for more on this). In addition, specific requirements of national policies also often required changes to staff training. The need to maintain a good reputation also appeared to contribute to the outcome of increased marketability, given that reputation is important for securing future business. Finally, individual factors of personal definitions of PPI, relationship management (particularly internal organisation relationships), and integrity and honesty also appeared to influence various outcomes. PPI facilitators played a key role in negotiating outcomes with decision makers (as will be discussed in more depth in the next section), and as such, their beliefs and skills appeared to contribute to achieving change.

Figure 28: Factors that contribute to outcomes and impact



The conceptual framework presented above highlights how complex PPI appeared to be in these three organisations. Indeed, the factors presented in this framework are certainly not exhaustive – there were numerous other factors identified, as already highlighted in Table 17 in section 3.1. showing the development of codes from the data. Reflecting back on sections 1.6.1-6, the conceptual framework presented here has arguably achieved what others previously have not – an extensive presentation of the multifaceted nature of PPI. Dachler & Wilpert's (1978) argued that models and theories could be categorised into four groups: democracy theory, socialist theory, human growth and development theory, and productivity and efficiency theory. The conceptual framework presented from this PhD study arguably covers all four categories. The political and societal factors highlighted draw upon democratic and socialist theories – PPI sometimes serves as an attempt by organisations to be accountable to the public. The individual factors highlighted draw upon human growth and development theory, such as the notion that PPI helps develop people (both professionals and laypeople). Finally, numerous organisational factors highlighted draw upon productivity and efficiency theory, such as quality improvement being a driver for PPI and the potential for services to be more efficient as a result of PPI.

4.9. PPI facilitators – negotiator, gatekeeper, and peacemaker

Throughout the analysis, it became apparent that PPI facilitators operate in a mediating, and sometimes negotiating, role between organisations, and patients and the public; particularly considering the three tensions detailed in sections 4.7.1-3. In this sense, one could argue they operate in similar ways and have similar identities to trade union representatives, or perhaps human resource managers. They could be argued to be a ‘hybrid’ role of employee/professional and patient/public representative. The present research suggests that this emerging role is worthy of further detailed examination (see section 4.12.1. for suggestions for further research).

As an example of research into ‘hybrid’ roles in healthcare, McGirven et al. (2015) studied the ‘hybridization’ of medical professionals in managerial contexts and how they maintain their professional identity alongside their management roles. Although PPI facilitators were not from a specific profession group (such as medics or nurses); their varied hybrid-like roles potentially lead to complex constructions of identity and sense of worth, similarly to the medics studied by McGirven et al. (2015). As already discussed, their motivations were similar to the laypeople, and as such, they may have aligned their identity more closely with the laypeople than their colleagues (see section 4.4.2.). This potentially presents an internal conflict for PPI facilitators, in that they are neither an insider (with their colleagues) nor an outsider (with patients and the public).

In another sense, they also indicated that they offer themselves as gatekeeper to the organisation for patients and the public, often even determining who gets access to the organisation. This means they have a potentially underrated level of power in determining the nature of the relationship between communities and the organisation. As they are the first contact for many patient and public representatives and groups, the level of access and nature of activities people can get involved in are potentially at least partly determined by the PPI facilitators. They have an important role, for example, in recruiting members for focus groups, projects, and committees; and act as a conduit between laypeople and services. A similar finding was noted by Tenbenschel (2002; as cited in Li et al., 2015) that there are mediators between the public and decision-makers in the context of public involvement in health policy decisions. These mediators are key to aiding decision-makers’ interpretations of the public input. PPI facilitators play the same role in their organisations to deliver service

change. Similarly, Li et al. (2015) found that public involvement practitioners they interviewed identified their role as two-fold – “trusted advisor to the organizational leadership and champion for community residents” (p.17). It is argued here that PPI facilitators in the present study had the same dual roles, as described in section 4.4.2.

Furthermore, a key part of their role could be argued to be conflict management. Not only did their role require bringing together professionals and patients and the public, but they also must bring together a range of professionals, all of whom come with their own beliefs and motivations. Involved in PPI activities were managers (both corporate and service-level), nursing staff, professionals with specific expertise (e.g. chaplaincy), charitable organisation representatives, and laypeople (whom all came from a range of backgrounds as well, including key professions such as nurses, teachers, and councillors). Interestingly, it was noted that there was only one PPI activity that included medical staff involvement (this issue will be returned to in section 4.12.2.).

Given the range of professions and backgrounds amongst these individuals, conflicts often did arise. Though these conflicts were never aggressive in nature, they were relatively frequent. Not only would laypeople and professionals challenge one another, but profession group members would challenge those from other profession groups too, whilst simultaneously defending others within their profession groups. There were even some non-verbal behaviours that suggested individuals wished to group together with those of the same profession (e.g. sitting together with people of the same profession or team/department). PPI facilitators (who often led these meetings and activities) had the challenging task of managing these conflicts in a diplomatic manner to ensure everyone had the opportunity to speak without anyone being unduly challenged or undermined. In Staley’s (2015) study of PPI in research, the influence facilitators have over the conduct and impact of PPI was identified, and the following quote summarises these issues:

“In practice, it is therefore often the researcher who directly experiences the impact of involvement. It is their thinking, planning, values, and communication that are often challenged through involvement...For this reason, the impact of involvement could be more usefully conceived as a form of experiential knowledge. In the same way that patients’ knowledge is gained through direct experience of a health condition, researchers’ understanding of involvement is

gained through their direct experience of working with patients/the public. Knowledge...is therefore 'knowledge in context', which is different in nature and quality to 'evidence' obtained through systematic enquiry". (p.7)

These conflicts and multifaceted roles potentially involve considerable emotional labour and can be very challenging for PPI facilitators to manage. Staniszewska (2009) pointed this out in an overview of the literature on PPI, particularly because these individuals often work in isolation or in very small teams, as also demonstrated in the present study. The lack of support for PPI facilitators forms one of the recommendations for future practice (see section 4.12.2.). Staniszewska states that:

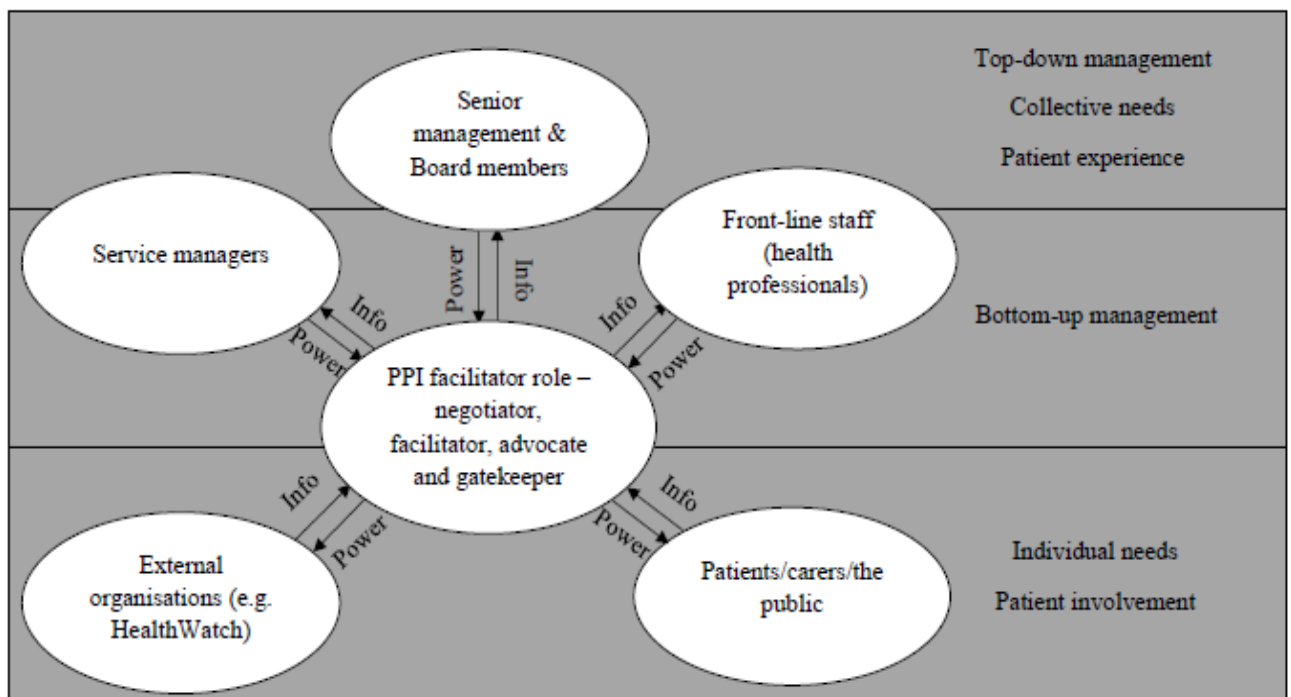
"individuals leading patient and public involvement activities often find themselves trying to change the culture of large healthcare organisations. These individuals face significant challenges and require support. However, in the UK setting such individuals are often working on their own as the key driver of this cultural change, which can be very isolating. Such experiences have many resonances with the concept of emotional labour present in nursing." (p.297).

The PPI facilitators in the present study articulated clearly the challenges of their roles, and cited numerous barriers to achieving their remit. Many suggested that their role was essentially limited by its position within the organisation: they were not Directors with significant decision-making powers at the corporate level, nor were they managers of services with decision-making powers at the local service level. As such, it was only within their power to try to influence both senior management for organisation-wide change, and general managers and clinicians for localised service changes, through the provision of information on patients'/laypersons' views. To illustrate this negotiating and brokering role, Figure 29 shows the different groups of stakeholders they interact with, indicating whom has power over whom, and the information exchanging role PPI facilitators have.

Furthermore, the three tensions described in sections 4.7.1-3 appeared to be influencing many of the relationships between these key stakeholders. The tensions between top-down and bottom-up management clearly influenced many of the processes and decision-making powers – PPI facilitators often needed the support of senior management to make decisions, but also needed support from service managers and health professionals to carry out change

needed. The ongoing tension between individual and collective needs also had influence over processes and decisions in that senior management reportedly often needed to balance personal patient stories against the bigger priorities of the organisation and wider needs of the community. Finally, the third tension between monitoring patient experience measures and conducting targeted PPI work influenced these stakeholders in that Board members and senior managers were reportedly more interested in statistics and figures, whilst PPI facilitators and service-level staff were more interested in conducting targeted PPI work specific to their patients or specific groups.

Figure 29: PPI facilitator role – power and information exchanges



4.10. Contribution to new knowledge

This section summarises the contribution to new knowledge. As demonstrated in section 4.8., the data collected was used to construct a conceptual framework. Some elements of the framework confirmed previous findings in the literature, whilst other elements added nuances to existing findings, or were new findings. The majority of new or nuanced findings were within Organisational Factors. The likely reason for this was the way in which the research was conducted and where the focus of the research lay. By conducting case study research with a key focus on organisational processes, structures, hierarchies, policies, etc., the data collected shed light on factors not previously explored in depth.

More importantly, the data highlighted how influential this group of factors can be on the conduct of individuals working in the organisation, and, as such, the way in which PPI work is conducted. In turn, this has key implications for the actual and potential outcomes and impact of PPI. As there were such a wide variety of factors that had not previously been researched in depth before, to aid the reader, Table 20 summarises the key factors that are new or added nuances to existing literature, with an explanation regarding how they do so.

Table 20: Summary of new or nuanced findings

Factor name	How it adds to literature	Relevant section/s of literature review and discussion
Technological age	Although there has been more research done recently on the use of digital technology to engage patients and the public, the present study adds to this by highlighting how it is contributing to consumerist attitudes towards healthcare and changing the nature of conversations between healthcare organisations and their patients and the public.	1.2.3. 4.2.2.
Board support	This finding was very specific to the present study. Although few Board members were interviewed and/or observed, there were many references in the data to the impact of explicit	N/A in literature 4.3.1.

	Board support for and understanding of PPI. The nature of their support had an impact on the resources allocated and the capacity of roles.	
Capacity of roles	Although there are references in the literature to roles and tasks in PPI, the present study highlights more specifically the limited capacity of particular roles, especially those of PPI facilitators.	1.3.3-4. 4.3.1. & 4.9.
Staff engagement	Though there is much wider organisational research on staff engagement, there has not been explicit references to this in the context of PPI.	N/A in literature 4.3.1.
How roles are defined	Similarly to ‘Capacity of roles’, the present study has highlighted that how roles are defined isn’t necessarily merely about tasks and personal identification with the role. It is also about how roles and tasks have been defined according to organisational priorities and workstreams.	1.3.3-4. 4.3.1.
Culture of mental health vs. medical model	Whilst there are references in the literature to the paternalistic nature of healthcare in general and in relation to a lack of power-sharing in PPI, the present study added to this by highlighting the potential differences between cultures in mental health and acute healthcare organisations. This was particularly surprising given the many references in the literature to a highly paternalistic culture in mental health – the present study found quite the opposite – a culture of partnership and openness with patients and the public.	1.3.4. 4.3.4.
Competing priorities: Efficiency savings, Patient safety and Targets & KPIs	This group of identified factors were new findings. There had been no specific research that took into consideration competing priorities in healthcare organisations and their impact on both the nature of PPI work and its potential outcomes. The present study demonstrated how constrained staff were by competing priorities.	N/A in literature 4.3.2.

Lack of clear PPI strategy	Again, this was a new finding. There had not been references to organisations having specific PPI strategies, with the exception of Lightfoot & Sloper (2003) in the context of PPI in children’s healthcare, whom said PPI was not linked to wider organisational strategies. The present study highlighted the lack of direction some individuals felt when there wasn’t a clear strategy, but findings also indicated having a strategy didn’t necessarily lead to greater clarity on roles and tasks.	N/A in literature 4.3.3.
Reputation management	There has been research into the general need for healthcare organisations to be accountable and how this has driven increases in PPI over the years. However, the present study added nuances to this in highlighting that reputation management appeared to be a specific driver for some PPI work – it wasn’t just about being accountable, but also demonstrating they are open for the purpose of maintaining or improving their reputation.	1.1.3. 4.2.3.
Personal definition of PPI	Whilst there is plenty of research on how PPI is defined and the lack of consistency of definitions, there seemed to be a lack of consideration for how individuals (specifically professionals) defined PPI and the resulting impact this had on its conduct.	See intro to literature and 1.6.1-6. 4.4.3.
Personal stories vs. bigger picture	Whilst there were some references to how staff can undermine patient stories by arguing they are too personal and not relevant, the present study added to this by highlighting that this was a highly prevalent belief amongst staff, and that this presents a considerable challenge for PPI facilitators when negotiating with front-line staff and senior managers about service developments.	1.3.4. 4.7.2. 4.9.

Integrity and honesty	This was also a new finding – this finding related specifically to PPI facilitators and their abilities to be open and frank with patients and the public about how involved they could really be. There are references in the literature to the importance of being clear on roles and the boundaries of those roles, but the present study highlighted how important this personal trait was for PPI facilitators in their conduct and maintaining relationships with communities.	1.3.3. 4.9.
Networking	Whilst there are references in the literature to the unrepresentativeness of participants and the specific issue of the same people being recruited for multiple activities, forming an ‘in-crowd’, the present study adds to this finding by highlighting that this happens due to the combined networking behaviours of both PPI facilitators and laypeople. The present study also highlighted how strongly this links to recruitment methods – PPI facilitators resorted to using existing contacts for practical reasons.	1.2.1. 4.4.2. & 4.9.

4.11. Limitations of the research

The next two sections describe the acknowledged limitations with the methodological approach as well as specific limitations with the individual methods. There were some questions raised as a result of the findings that were unable to be fully explored within the time constraints and limits of the present study. As such, recommendations for further research will follow in sections 4.12.1-4.

4.11.1. Limitations of the methodological approach

Qualitative research has often been criticised for being subjective and incapable of being generalised to other contexts. The criticisms of qualitative research concerning subjectivity and unreliability come from what Yin (2009) described as a misconception in research methods that they should be seen in a hierarchy. By this he means that some researchers assume that qualitative case study research should only be used as a preliminary investigation, and that experiments (particularly randomised controlled trials) are the only way to find probable causality. Yin (2009) argues that case study research can be explanatory and not just exploratory. This was the stance taken in this research. The aim is to identify and explain how PPI works in different social contexts with different social influences and different stakeholders participating.

The other common criticism of qualitative case study research is that it cannot be generalised, in that a single case study cannot be the basis for scientific interpretation. Yin (2009) argues that this is equally true for experiments – you cannot generalise from one experiment. Yin (2009) argues that scientific interpretations are made from a series of experiments or cases. Therefore, in the current research, interpretations were made from more than one case and from evidence collected from numerous sources within each case site. The themes and concepts identified and the conceptual framework within which they are defined can then be extrapolated to other healthcare providers, if at least in a conceptual way. For example, the notion of consumerism and increased ‘customer’ expectations can be a challenge for all healthcare providers, not just the ones observed in this research. Also, by examining three very different healthcare organisations that represent a broad sample of the healthcare sector, the findings should be largely applicable to other organisations. Essentially, the findings can be generalised conceptually rather than to a specific population, as they should resonate in other healthcare providers.

4.11.2. Limitations of the research methods

Regarding each data collection method specifically, there were potential limitations and weaknesses that needed to be addressed. Yin (2009) provides the following succinct summary (Table 21) of the strengths and weaknesses of each data collection method chosen for this research. Following this summary, descriptions of how these limitations were avoided or mitigated against in the present research have been provided.

Table 21: Sources of evidence: Strengths and weaknesses (Yin, 2009: p.102)

Source of evidence	Strengths	Weaknesses
Documentation	<p>Stable – can be reviewed repeatedly</p> <p>Unobtrusive – not created as a result of the case study</p> <p>Exact – contains exact names, references, and details of an event</p> <p>Broad coverage – long span of time, many events, and many settings</p>	<p>Retrievability – can be difficult to find</p> <p>Biased selectivity – if collection is incomplete</p> <p>Reporting bias – reflects (unknown) bias of author</p> <p>Access – may be deliberately withheld</p>
Interviews	<p>Targeted – focuses directly on case study topics</p> <p>Insightful – provides perceived causal inferences and explanations</p>	<p>Bias due to poorly articulated questions</p> <p>Response bias</p> <p>Inaccuracies due to poor recall</p> <p>Reflexivity – interviewee gives what interviewer wants to hear</p>
Direct observations	<p>Reality – covers event in real time</p> <p>Contextual – covers context of case</p>	<p>Time-consuming</p> <p>Selectivity – broad coverage difficult without team of observers</p> <p>Reflexivity – event may proceed differently because it is being observed</p> <p>Cost – hours needed by human observers</p>

Documentation

Regarding the limitations concerning documentation, the issues of access and retrievability were not major concerns. As the PPI activities observed all tended to involve use of various documents (e.g. agendas), getting access to the documents was not an issue. There were often spare copies tabled for participants to use. At each observation, permission was sought from the chair or facilitator to take copies of documents used during the activity. There were no obvious efforts from any participant to deny access to any documents. Furthermore, several were already in the public domain (such as Quality Accounts), and so easy to retrieve. With regards to author bias, this was indeed a concern. However, as already described in section 2.2.3., identifying the way in which employees of the organisation present important information regarding PPI to the public was an aim of the study. Therefore, the potential 'bias' of the author was a deliberate line of inquiry.

Interviews

In addition to Yin's (2009) summary of weaknesses of each method, Easterby-Smith et al. (2012) also describe six main potential practical difficulties specific to conducting interviews: obtaining trust, social interaction, using the appropriate language, getting access, choosing the location of the interview, and recording interviews. As for obtaining trust and getting access, interviews only began after at least 3 months of observations. This allowed for both the practicalities of having a reasonable amount of content to discuss with the participant, and allowing a rapport to build. By building a good relationship with these individuals prior to interviewing them, interview data became more extensive than perhaps it would have been had the only method been to interview them.

Also, by conducting observations first (and alongside interviews), this ensured the language used during the posing of questions was appropriate to the context. For example, within MHT, the participants tended to use the term 'service user' rather than 'patient'. Participants were offered flexibility of location for the interview – most requested to be interviewed in their place of work, which usually meant conducting the interview in a private office. This allowed the participant to feel comfortable and to ensure confidentiality was maintained. Only one participant opted to be interviewed with a colleague present (who had already been interviewed as an individual previously). All interviews were digitally recorded to aid transcription. Interviews were transcribed verbatim and descriptions of expressions,

body language, tone, exclamation, and behaviours were added for additional interpretation of the data during the analysis process.

Observations

In terms of the limitations of conducting observations, they were indeed time-consuming and costly (travel expenses for example). These issues were, of course, unavoidable. Financial costs were covered within the secured studentship award. As for the time cost, there was little that could be done to mitigate against this, other than to utilise all available other time to write up and analyse observation notes to make best use of time. Capturing the broad content of the activities was challenging given that there was not a team of observers present. However, personal strong skills of note taking and recall aided production of a detailed record of observation data. If there were gaps in notes, the chairs and facilitators of activities were contacted to clarify or confirm content to ensure notes were typed up as accurately as possible.

The final weakness identified by Yin (2009) of reflexivity (the participants behaving differently because of being observed) did not appear to be a problem. As already described in section 2.2.1, the participants did not change behaviours over multiple observations, suggesting that they were adopting their usual behaviours. Most activities observed were recurring activities (e.g. committees) and, therefore, participants already had established agendas, formats, and relationships with one another. This may be why there were no observed behaviour changes over time, which supports an argument that being observed is not likely to have affected their behaviours.

Another acknowledged limitation of the observational data was the differing activities that were observed, meaning that some themes could not be analysed across all three case sites. Specifically, two types of activities were only observed in specific case sites – there were no focus groups in MHT and no governance meetings in SE. The lack of observation of focus groups in MHT was simply due to not having access to any. This is not to say that MHT staff never conduct focus groups but simply that either, a) none occurred during the data collection period, or b) none were known to be occurring by PPI facilitators, whom were the main contacts when identifying activities to observe.

With regards to the lack of observation of governance meetings at SE, this was due to refused access. Senior managers were approached by the PPI lead to request permission for governance meetings where patient experience and involvement were discussed to be observed, but unfortunately, they refused. The PPI lead was only able to say that managers were concerned that other more sensitive information discussed at these meetings should not be observed. An offer was made to only record relevant information during observations, but managers continued to deny access.

One of the reasons three different organisations were examined was to assess the range of methods of PPI used in different contexts. As such, whilst it is unlikely that the present study captures all activities the organisation conducts, the range of activities observed and described by participants was subtly different in each organisation. These differences have already been described in section 4.3.4. The argument here is that, whilst different activities were observed in each case site and, therefore, cannot be compared directly, the differences observed were not necessarily a weakness of the methods, and were instead indicative of the importance of context.

On a final note, a considerable amount of data analysis was conducted on interview data, rather than observational data and document reviews. However, as pointed out in the Methodology, observations provided data that confirmed or added nuances to interview data, such as witnessing behaviours and interactions between stakeholders that added to the individual perspectives of these relationships reported in interviews. Documents were important in providing contextual information, such as the content of reports, which demonstrated the higher prevalence of reporting of patient experience figures and complaints numbers than reporting of PPI work. As such, although a considerable amount of interview data is referenced in the Results, the additional data sources allowed for a more comprehensive analysis process, without which a detailed conceptual framework could not have been developed.

4.12. Implications for further research

The following sections make suggestions for further research. Although the present study involved a comprehensive review of evidence across three large organisations, there were specific issues that could not be explored in depth and may require further research. Firstly, given the multifaceted role of PPI facilitators specifically, one of the suggestions is for further detailed examination of their roles across multiple organisations. Secondly, as PPI roles and responsibilities were conducted within the nursing hierarchies in all three organisations, it is suggested this could be explored across other organisations to establish if this is common practice. Thirdly, as there was some suggestion PPI could be used by senior management as a performance or change management tool, further examination of this concept may be needed. Finally, as a key finding was the different cultures apparent in MHT and AHFT, a suggestion is made that it should be established if these cultures are specific to mental health and acute health organisations, and further examine the potential impact on PPI.

4.12.1. Further examination of PPI facilitators

As already discussed in section 4.9., PPI facilitators have a unique and complex negotiator-gatekeeper role in their organisations. They take on the role of advocate for patients and the public, and must simultaneously be representatives of their organisation. Their work roles are varied, and cross social and professional groups. Given the identified importance of their roles in these three case studies, it could be beneficial to examine the PPI facilitator role specifically in more depth.

As the present study only involved three healthcare organisations, a limited number of PPI facilitators were interviewed (all three case sites had between 5 and 10 individuals in dedicated PPI roles, and around half of these were interviewed, though all were observed at least once). As such, it is not clear how much the perceptions of these individuals might resonate with PPI facilitators in other healthcare organisations. To further explore and examine their roles, identity perspectives, and personal skills, it may be pertinent to conduct a study specifically exploring these issues. This could be done by way of a survey of PPI facilitators across multiple organisations, or a series of interviews. In depth interviews would likely highlight many of the factors already found in this research, but may offer a wider range of perspectives from this important group of individuals. It could also illuminate more

about this group's motivations, histories, and backgrounds, which Barnes et al. (2006) suggested is important to understand. Focus groups could also yield interesting findings by bringing these individuals together to debate the issues pertinent to their roles.

Secondly, as the present study identified PPI facilitators often experience conflict and resistance from front-line clinicians and service managers, it would be pertinent to explicitly examine the perceptions these individuals have of PPI facilitators. Understanding these perceptions, and conflicts associated with those perceptions, could yield data that would aid greater understanding of the impact/lack of impact of PPI. If PPI facilitators are continuously faced with resistance from these individuals, PPI is unlikely to have much impact.

4.12.2. Why is patient experience and involvement the nursing professions' role?

In some ways related to the previous recommendation for further research is the issue of why PPI activities are conducted within nursing governance structures. One of the findings of the present research was that patient experience and PPI activities were conducted by people who worked within the quality governance directorates of these organisations, which were managed by senior nurses (or at least managers from a nursing background). In all three case sites, executive responsibility for it fell on the Chief Nurse. Although it is not possible to state that this is standard across all healthcare providers, there is other research that suggests these tasks and roles have historically been seen as the nursing profession's responsibility, as identified by Bolton (2002) for example.

In several observations, the lack of medical profession representation in PPI activities was noted, and, indeed, was included as an important finding in reports to the organisations. Informal conversations with various professionals during the research period, and from experiences as a practitioner, provide anecdotal evidence that the lack of medical involvement in PPI work cannot be solely explained from the medical professions' personal perspective (e.g. a lack of willingness on their part). There were examples of managers from a nursing background and senior nursing staff suggesting that medical involvement was not necessary for the task in hand, or that the medical profession would not wish to be involved. However, there was no evidence that medical professionals had actually been approached to be involved – the decision had already been made not to involve them. There was only one exception. In MHT, a major project that involved patients also had medical profession involvement – a psychiatrist and a GP; and this was specifically indicated as a valuable

contribution by two interviewees involved in the project. And although these individuals did not specifically give examples of the impact of medical staff involvement, they did report it being beneficial by providing technical and medical knowledge contributions.

The dynamics of these relationships and conflicts in the context of PPI work appears worthy of further research. Given that a PPI facilitator's key role is to bring together a range of stakeholders in PPI activities, it may be that whilst studying PPI facilitators' roles in more depth, it would be pertinent to assess relationships between the other stakeholder groups. The present research demonstrated how key their role is in bringing the patient voice to professionals and managers. There were no examples, other than the one stated above, of PPI facilitators engaging with the medical profession. This all suggests that PPI facilitators do not necessarily bring together all stakeholders. If PPI continues to be the nursing profession's responsibility and continues to be placed in the nursing hierarchical structures, it is possible that gaining meaningful medical engagement will be slow in progressing, or will not progress at all.

4.12.3. Is PPI merely a performance management tool?

As already discussed in section 4.6.1., PPI sometimes resulted in changes (or proposed changes) to staff training and development. This was indicative of an assumption that staff were directly (or at least partly) responsible for poor patient experiences and that their behaviours needed to change as a result. Some have suggested patient feedback and PPI are used as performance management tools by senior managers (Bolton, 2002; Milewa et al., 2004). However, the present study found that PPI facilitators (not senior managers) were responsible for making recommendations for change based on patient views, therefore, it was not a direct performance management tool. Having said this, there is the possibility that senior managers in central corporate roles may utilise the work of PPI facilitators to performance manage front-line staff and service managers.

As already reported, PPI facilitators faced resistance to change based on PPI activities from front-line staff, but they also faced a lack of support at times from senior management. They reported often having to compete with other wider organisational priorities and the work of other teams and departments. Therefore, it may be possible that senior managers only supported PPI facilitators in implementing service changes from PPI if it suited organisational priorities. As a hypothetical example, if senior managers wished to persuade

consultant surgeons to amend theatre schedules, and patient feedback happened to be negative about existing arrangements, senior managers may then see this as an opportunity to justify the changes they wish to make. It is potentially more persuasive for senior managers to use patient feedback to justify organisational change, rather than order the changes directly. This is precisely the suggestion made by Bolton (2002) – that patient feedback is merely used to legitimise changes managers already wish to make.

As few senior managers were interviewed or observed directly, this is currently speculation. To assess if PPI and patient experience serves as mainly a performance-management tool, or an aid for change management, the perspectives of these managers would need to be explored in more depth. In the present study, the line managers of all the PPI facilitators were interviewed, but only one Board member was interviewed in SE and none in the other two sites. As such, it is difficult to assess what main purpose PPI really served for senior managers. In depth interviews with senior managers, particularly Board members, could provide insight into the perceived uses of PPI. If their emphasis is on changing staff behaviours, this may be suggestive that it is indeed a performance-management tool. If the emphasis is on what is good for patients and the public, this would suggest otherwise.

4.12.4. The effects of culture and ethos on PPI acceptance

As discussed in section 4.3.4, there was some evidence in this study of two very different organisational cultures between MHT and AHFT – the holistic model and the medical model of care respectively. The paternalistic culture in AHFT appeared to not sit comfortably with the concepts of PPI – partnership and shared decision-making. At the other end of the spectrum, the holistic culture apparently present (according to interviewees) in MHT seemed to make PPI more acceptable and comfortable to staff. As these were only two healthcare organisations, it is not clear if these cultures were specific to them and the difference in the type of provider was merely coincidental, or whether this was indicative of different cultures in mental health and acute health.

As such, it would be pertinent to explore if:

- a) the paternalistic culture is indeed more evident in acute hospitals than mental health providers, and the holistic care culture more evident in mental health providers than acute hospitals;

- b) this difference in culture type has an influence on the acceptance of PPI by staff, and approaches of PPI methods, as well as outcomes and impact.

If the PPI facilitators' suggestions are correct that PPI is more successfully adopted by mental health trusts than acute trusts, this will further aid our understanding about how PPI works in different settings. What would add to the findings of the present study would be to identify if these cultural influences are present in other similar organisations. This in turn could lead to more tailored and practical recommendations for different healthcare providers.

4.13. Implications for practice

It was important that, in addition to contributing to existing knowledge of PPI, the research would have practical application and potential impact. Staniszewska (2009) recommended that “increasing attention needs to be focused on how our knowledge of involvement, what works well and in what context, and how it can be translated into practice within service development” (p.297) in future PPI research. As such, a key aim of the study was to identify good practice, as well as facilitating factors and barriers, to be able to make recommendations for practical application.

At the end of the second year of study (and the end of the data collection phase), I obtained employment at one of the case study sites. This allowed me to work with PPI staff and other professionals to put into practice some of the findings from the research. Furthermore, all three organisations were provided with a report detailing my observations of their PPI processes and my recommendations for how they might improve PPI processes and their impact. SE responded to a follow up contact and provided details of the ways in which those recommendations have been utilised. Unfortunately, MHT was not able to provide a response due to significant personnel changes. Below is a summary of the key developments in both the social enterprise and the acute trust I am now employed by, linked to each of the recommendations in the reports provided to them.

4.13.1. Reported outcomes of the research

SE: Social Enterprise

Recommendation 1: To avoid an over-reliance on surveys and diversify methods of PPI. Although many surveys are imposed by the Government, a range of other methods should be employed to make PPI as meaningful as possible in various contexts. (It should be noted that the two NHS Trusts were more reliant on surveys than SE, despite having more staff resources.)

Action/s taken: SE’s Patient & Public Engagement (PPE) team has been working to develop a wide range of feedback processes across the organisation. Surveys are still distributed to patients/service users to complete at the end of an intervention. These can be submitted by paper, and staff with mobile working devices can now encourage people to

submit them using the device. But in addition, SE has developed other methods of feedback including: comments boxes and comment cards in all health centres and venues where their services are delivered; a compliments database, enabling staff to quickly log any feedback received through thank you cards and verbal feedback from patients; opportunity for people to give feedback online via the organisation's public-facing website; and continued opportunities to give feedback through the 'Patient Experience Group', which consists of multiple patient and voluntary sector representatives. The Head of PPE has also met with the Interpreting Service to encourage interpreters to feedback information on behalf of patients; and the Primary Care Learning Disability Service has been looking at a new model of visiting people with learning disabilities at home after accessing a service to gather feedback more effectively.

Recommendation 2: Diversify participation – several people raised an issue of unrepresentativeness, including laypeople. The key message here is that no provider of health services should come to rely on the voices of one group. SE staff have already recognised that their main PPI function, the Patient Experience Group (PEG), is not very representative of their city's population and so it should not always be the default choice for seeking involvement.

Action/s taken: SE have reviewed their PEG membership and a number of additions have been made, including a mental health charity that addresses mental health issues in BME communities. Furthermore, a grading event took place in December 2015 in relation to the organisation's compliance with the Equality Delivery System. A range of stakeholders (lay representatives and professionals) representing protected characteristics (Equality Act 2010) attended and participated, and the information gathered fed into the Annual Quality Account consultation. The PPE team also works closely with HealthWatch, who identify issues in specific communities, and the work described under the previous recommendation regarding the Learning Disabilities service also addresses representativeness.

Recommendation 3: Consider expanding people resources – SE's involvement and engagement staffing resource centrally is very limited, especially in comparison with the two NHS Trusts. Whilst financial resources are clearly very limited in these austere times, there was a clear need for greater investment of time and resources centrally to enable the team to meet their PPI strategy. The strategy itself is very comprehensive and considers all elements

of involvement, much of which involves activities that are time consuming and resource-heavy and, therefore, the Board and senior management must determine how this strategy can be met given the limited existing resources. Volunteers, for example, could assist in some activities.

Action/s taken: The resource within the team has not increased and this is reportedly looking unlikely. However, the team regularly reviews workload and agrees realistic targets based on available resources. Volunteering has also not progressed to date.

Recommendation 4: Develop capacity of front line staff – the issue of front line staff being unable to involve their patients in service developments was a reported barrier for this case site. Reports suggested front line staff were either not aware that they should be responsible for leading service developments, or simply didn't have the time. The central team's role is one of facilitation but if the time is not built into front line staff members' roles, it makes facilitation difficult. The organisation could consider, for example, making service development part of appraisal processes for staff, and training should be offered to those who have a keen interest.

Action/s taken: There is some work planned to look at how this could be done more effectively in children's services, as they are now mostly commissioned by the Local Authority and incorporate a wider public health/health promotion role. Some pilot work has been carried out by the school health team and supported by the PPE team.

AHFT: Acute Hospital Foundation Trust

Recommendation 1: To implement and establish a dedicated team at a corporate level within the organisation to coordinate improving patient experience projects and developmental work. This will provide a more coordinated and strategic approach rather than the focus being pulled to managing formal complaints and meeting targets.

Action/s taken: A Patient Experience Team was established late in 2013 consisting of a Project Coordinator, an Engagement Officer, part-time admin (all three of whom were moved from other areas such as the Complaints team), and a new post of Patient Experience Manager to manage the team. The manager and the team reported to the new Associate Director for Patient Experience who reported to the Chief Nurse. Crucially, the new role of

Associate Director did not manage formal complaints and the Patient Advice & Liaison Service (PALS), which had pulled the previous Director in multiple directions. Instead, the role of managing formal complaints and PALS was handed to the Deputy Chief Nurse. This meant that the new team, distinctly separate to complaints and PALS, could focus more on developmental and strategic work.

Recommendation 2: Encourage greater engagement from the medical profession – PPI sits within the senior nursing structure and is ultimately the responsibility of the Chief Nurse (as with the other two case sites). This inevitably means that the medical profession does become side-lined somewhat. All activities observed in the Trust did not include any medical professionals – all were managers and those from the nursing and therapy professions. This is potentially leading to an untapped resource and expertise.

Action/s taken: This recommendation has been considerably more difficult to achieve than the first. The role of PPI still sits physically within the senior nursing structure but key changes include making both the Chief Nurse and Medical Director jointly responsible for patient experience (which includes PPI); creating a formal presentation for the Trust's induction programme (which is for all new staff including medics) that focuses solely on patient experience and PPI; and finally, including senior medics on key service development programmes. One large-scale improvement project around discharge processes, for example, was headed up and led by a Senior Consultant.

Recommendation 3: Create a Trust-wide programme and strategy on patient engagement and improving patient experience to encourage a more coordinated and strategic approach rather than there being ad-hoc projects in pockets of the organisation. This will, firstly, help those in PPI roles to have a clearer direction to follow (many complained of feeling 'lost'), and secondly, ensure that the organisation as a whole is working together.

Action/s taken: A strategy for patient and public engagement was written and published in early 2015 after the team had been in place for just over a year. The strategy made it clear how the organisation was going to engage with its public and patients and their families (as well as key partners like HealthWatch) and what the purpose was (to continuously review and improve services).

Recommendation 4: Continue to expand on and utilise the library of ‘patient stories’ – the Trust had already begun collecting powerful patient stories to share with staff as part of training programmes and at key governance meetings, but the recommendation here was to continue to develop this piece of work and use powerful patient stories as widely as possible.

Action/s taken: The library of videoed patient stories has expanded hugely. The team have also now branched out to other methods of recording patient stories (such as written stories), and continue to review how they capture and use patient stories. The stories had already been used for training purposes and staff engagement, and at some governance meetings, but the frequency of their use in a key governance meeting has expanded to every meeting in its opening section and has recently begun being shown at every Board meeting. Furthermore, every story shown includes an action plan from it; even if it is a largely positive story (the key action plan from these has usually been to share best practice with other services within the Trust).

Recommendation 5: Expand the range of methods of PPI, to avoid over-reliance on surveys. This will ensure PPI is as robust and meaningful to the Trust as possible. Methods should include qualitative methods such as interviews and focus groups, as these provide more in-depth perspectives.

Action/s taken: Large-scale service improvement programmes now take a much more mixed-method approach that includes focus groups and interviews with patients and the public. Previously, the vast majority of projects involved a brief survey and then an action plan, sometimes with a survey at the end to understand the impact of changes made. Furthermore, many projects go further than this and include a patient representative on the project group. In addition, as the Patient Experience Team became more established, individual services came to the team for advice about how to engage and seek feedback from their patients in a more meaningful way. In addition, the use of social media to communicate and engage with the public has expanded – the Trust now actively uses its Twitter and Facebook accounts.

Recommendation 6: Put in place a more diverse range of recruitment methods for recruiting people to be involved in projects, to avoid over-reliance on Governors and people from existing networks who ‘know the system’. This will ensure that the lay perspective is

more truly ‘lay’ and not professionalised. Furthermore, roles of patient and public representatives should be clearly set out from the beginning to avoid confusion and overstepping boundaries.

Action/s taken: Unfortunately, due primarily to time pressures and capacity, many projects and improvement programmes, including audits, do still heavily involve Governors, HealthWatch representatives and people from existing PPI networks. However, the Trust has taken steps to more openly engage with its community by setting up dedicated pages on the website calling for patients and the public to get involved and give feedback, and the team also holds a series of engagement events throughout the year open to the general public. One factor that is out of the control of the Trust is the type of person who will respond – it is still primarily retired people who attend events and give feedback. It is worth noting, however, that young adults and those in their 40-50s are using social media more to communicate with the Trust rather than attend meetings, events and get involved in projects. This is most likely because it suits their lifestyle better.

4.13.2. Summary and recommendations for practice

This research has the unique value of already making some impact on practice, given the examples provided by two case sites above. The same or similar interventions may aid other healthcare organisations in much the same way. However, from the accounts provided by the PPI facilitators of these two organisations, improving PPI practices and increasing the success of it is challenging and may take considerably more time to fully embed. It may be possible to make further follow up contact with these organisations later to understand more about the progress they are making. The research also makes the following general observations that may be helpful to practitioners in the future:

- Senior management in healthcare organisations may need to define what they need PPI for and what role they expect of laypeople – strategies then need explicitly aligning with these definitions. If these definitions are not clear, PPI is likely to continue to have limited or no impact.
- The roles of PPI facilitators appear to be pivotal in PPI work and, therefore, need to be recognised and valued as the key contributors to achieving strategies. As such, they should be a key contributor to defining those strategies from the

beginning. Their roles should also be adequately supported and financed to respond to the demands of the role.

- The impact of competing priorities likely needs to be a bigger consideration in designing PPI strategies and plans. If PPI is important to an organisation's senior management, then efforts should be made to align PPI work with those priorities, rather than have PPI compete with other priorities, making facilitators compete for attention and support.
- Senior management may also need to alleviate as much as possible the constraints PPI facilitators experience and feel daily in their roles.

4.14. Conclusions

This study set out to examine in depth the complex social process of PPI in healthcare organisations – how it is conducted, what perceived purpose it serves, what factors influence its conduct and impact, what barriers there are, what roles different stakeholders have, and what (if any) outcomes and impact it produces. Identifying the key factors and how they interact then led to the production of a conceptual framework that demonstrates its multifaceted nature, and varying influencing factors. It builds on previous models and theories regarding PPI by making greater consideration of the wider factors of political and societal influences, and organisational contexts.

A major finding of the research was how integral PPI facilitators are to the process of PPI, in terms of how it is conducted, who is involved and how, and what outcomes there are as a result. Their important role has been arguably under-appreciated in the wider literature, with the notable exceptions of Barnes et al. (2006) and Staniszewska (2009). As Staniszewska (2009) pointed out, and what this PhD study also found, PPI facilitators can feel isolated and under-supported in their roles, facing the big challenges of changing organisational cultures and engaging with multiple stakeholder groups largely unaided. There was evidence that senior management did not appreciate the depth and breadth of their roles, including Board members, and PPI facilitators' knowledge and understanding of PPI was not shared by others, further adding to the isolation of their role.

However, despite being so embedded in the PPI process, PPI facilitators, like other stakeholders interviewed, struggled to clearly define PPI. It seems that people, even those close to the PPI process, lack clarity and are unable to move beyond abstract and context-specific interpretations of PPI. This is not necessarily a bad thing, but rather this may be the inherent reality of PPI. By its very nature, it is heavily contextually dependent and, as such, difficult to attribute a consistent definition and assessment of the impact. The effects of PPI are likely to be subtle and evolve over long periods of time, and indeed one of the main effects may simply be that PPI leads to more PPI. As increasing numbers of healthcare workers are exposed to PPI activities, the appreciation and understanding of PPI grows, and subsequently the will to increase PPI activities spreads across organisations. It becomes a continually growing practice across organisations, continuously changing the relationship between patients and the public, and healthcare professionals.

Furthermore, the study also identified three important tensions underlying PPI: top-down versus bottom-up management, individual versus collective needs, and patient experience versus patient involvement. These tensions have been alluded to in the wider literature before, but what the study adds is the identification that these tensions co-exist in healthcare organisations, and that it is PPI facilitators whom attempt to balance these tensions. Again, an important point to take forward is how integral PPI facilitators are in organisations when attempting to make PPI more effective.

The recommendations made in the previous section centre on supporting PPI facilitators better to continue to balance these tensions, break down barriers, and make PPI a success. As PPI facilitators do indeed appear to be so integral to PPI processes, it is important to value and support them in their roles. As already described, these individuals can feel isolated, under-valued, and suppressed by their organisations and the wider NHS system. If adequate support is not offered to these individuals, they will either succumb to the organisational constraints, or leave their role (or even the organisation altogether). As one participant described it, they will either “comply or die” (IC002).

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Lastly, and by no means least, I would like to thank my family who have provided invaluable emotional and practical support. My partner Paul and mother Sue have always encouraged me to keep going, and they have helped look after my beautiful children when I needed valuable protected time to write my thesis.

Appendix 1 - Interview topic guide for staff

What is your role in this organisation?

- *Prompt – background (e.g. nursing) and length of service*
- *Prompt – level within organisation (e.g. senior manager)*

What is your role with regards to PPI? How did you become involved in PPI?

- *Prompt – specific job role, or given as a responsibility?*
- *Prompt – voluntary additional support?*
- *Prompt – motivations*
- *Prompt – how they define PPI*

If not specific role in PPI, how much does PPI fit into your role?

- *Prompt – how important is participation to them?*
- *Prompt – is it an important part of their role?*
- *Prompt – motivations to involve patients*

What Patient & Public Involvement (PPI) activities are you involved in?

- *Prompt – specific projects*
- *Prompt – development of strategies*
- *Prompt – feed into other roles (e.g. performance management)*
- *Prompt – reports (e.g. to Board?)*

What regular group/strategy meetings are in place for PPI?

- *Prompt – how were these groups established*
- *Prompt – how are they organised (part of wider projects or work-streams?)*
- *Prompt – how are agendas developed*
- *Prompt – how formal, where and who*
- *Prompt – any specific issues*

What other stakeholders do you work with in terms of PPI? (e.g. commissioners, voluntary sector, local authority, LINKs, etc.)

- *Prompt – quality of relationships*
- *Prompt – influence of other stakeholders*
- *Prompt – effect on their role*

If not aware of anything at all, move on to following questions.

What are your general feelings about involving patients and the public in healthcare service decisions?

- *Prompt – how appropriate is it*
- *Prompt – how they feel about their role in the process*

How important do you think PPI is to your organisation on the whole?

- *Prompt – awareness at all levels?*
- *Prompt – competing priorities?*

How effective do you think PPI initiatives are in your organisation?

- *Prompt – what decisions has it influenced*
- *Prompt – facilitating factors/barriers*

What are the main difficulties you face in your role with regards to PPI?

- *Prompt – organisational barriers*
- *Prompt – professional boundaries*
- *Prompt – practicalities*

What do you think needs to change to make PPI more effective in this organisation?

- *Prompt – examples of best practice?*
- *Prompt – changes to system?*

How do you see PPI developing in your organisation going forward?

Future of your role (if directly involved in PPI): Will you be continuing in this role? How important is it to you?

- *Prompt – potential external factors, like lack of funding*
- *Prompt – motivations to leave PPI role/continue PPI role/adapt PPI role*

Any other comments?

Appendix 2 - Interview guide for lay people (patients and/or lay representatives)

How and why did you start becoming involved in these activities (refer to specific groups or meetings where they've been observed)? How long have you been coming to these sorts of activities?

- *Prompt – motivations to become involved*
- *Prompt – how did they hear about it*

What do you think effective participation is?

- *Prompt – how important is it to them*
- *Prompt – what do they feel are the benefits*

Can you describe how these activities (refer to specifics) work?

- *Prompt – who's involved?*
- *Prompt – agenda setting and reports elsewhere*
- *Prompt – how involved they are as a lay person*

What problems occur during these activities, if any?

What do you think are the good things about it?

How would you describe the interaction between professionals and people like yourself in these activities?

- *Prompt – content of conversations*
- *Prompt – length and quality of conversations*
- *Prompt – are there certain actors who lead more than others?*
- *Prompt – how much are you involved in the discussions?*

Have you seen any impact of your involvement? Can you give examples?

How involved are you outside of these activities?

- *Prompt – other activities and groups?*
- *Prompt – direct relationships with anyone in healthcare or other organisations*

How do you think the professionals feel about people like yourself being involved in these processes?

- *Prompt – any conflicts?*
- *Prompt – how positive are they about involvement*
- *Prompt – power relationships*
- *Prompt – how they behave towards patients and lay people*

Will you continue to be involved in these sorts of activities? Why and how?

- *Prompt – motivations for ending involvement or continuing*
- *Prompt – if meetings are part of a specific project, will they continue on with other activities?*

Any other comments?

Appendix 3 – Informed Consent Form

(to be completed after Participant Information Sheet has been read)

Please sign and date at the bottom of this form to indicate you understand and agree to the following statements:

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethical Advisory Committee.

I have read and understood the information sheet and this consent form.

I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in the study.

I understand that I have the right to withdraw from this study at any stage for any reason, and that I will not be required to explain my reasons for withdrawing.

I understand that all the information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others.

I agree to the recording of this interview and to the use of anonymised quotes in the write up of results.

I agree to participate in this study.

Your name _____

Your signature _____

Signature of investigator _____

Date _____

If you have provided consent on behalf of a person you are responsible for, please provide their name below.

Appendix 4 – Participant Information Sheet (PIS)

Patient and Public Involvement (PPI) in healthcare services

We would like to invite you to take part in this research. Before you decide whether you would like to take part, we would like you to read this information sheet which explains why and how the research will be done. Take a few moments to read this information. If you have any further questions before you agree to take part, please do not hesitate to contact the Main Investigator for this project. Contact details have been provided at the end of this sheet.

The Research Team

Main Investigator: Miss Sarah Todd, Doctoral Research Student, School of Business & Economics, Loughborough University, LE11 3TU

Academic Supervisors: Professor. Laurie Cohen and Mr John Loan-Clarke, School of Business & Economics, Loughborough University, LE11 3TU

What is the purpose of the study?

The aim of this study is to explore how different healthcare providers involve patients and the public in decisions about services. Observations and interviews will help to give a rich, real-life account of how it works, what the impact is, and how different people are involved in the process. This research should provide valuable insight that will help healthcare providers, commissioners and policy makers in the future. You have been invited to take part in an interview to supplement findings from observations that have already begun.

Why have I been invited?

You have been invited to take part in this study because you have been identified as someone who has a key role in patient and public involvement (PPI) either within the healthcare provider or an associated agency. You may be a member of staff who has a responsibility for PPI activities, or you may have worked on projects around patient experience and engagement, or you may be a public or patient representative on a committee or working group. Being identified in this way does not mean you are obliged to take part.

Do I have to take part?

No, taking part is entirely voluntary. You should read the rest of this information sheet and decide if you want to take part. You will be asked to complete a consent form if you agree.

What will happen to me if I take part?

The next few statements explain what exactly will happen if you agree to take part. If anything is unclear, please ask the researcher to explain further.

What will I be asked to do?

You will be interviewed about your experiences with regards to PPI. You will not be asked any questions about your personal life and health. You are not obliged to answer every question if you don't want to and are free to withdraw from the interview at any time. You may be asked to take part in further interviews throughout the research period. If you do not wish to be interviewed again, please inform the researcher. If you have already taken part in an interview, you are under no obligation to agree to be interviewed again.

What personal information will be required from me?

The only personal information needed from you is your name and contact details for the purpose of obtaining consent and contacting you again to arrange a further interview, should you agree to it. Personal information will not be kept by the researcher after the study, and any quotations used in publications and research reports will be anonymous.

Where will the research take place?

The interview can be conducted in a place of your choice (e.g. your work place or home). If you come to the University to be interviewed, you will be reimbursed with travel costs. Please note that interviews will be digitally recorded for transcription purposes. If you do not wish to be recorded, please indicate at the beginning of the interview. You may also request to be interviewed over the phone. Again, the interview will be recorded unless you request otherwise.

How long will it take?

The interview should take between 30 minutes and 2 hours, though it is difficult to give a firm timeframe for the interview, as everyone is different. How much information you give is

entirely up to you – you can refuse to answer specific questions if you wish. You are reminded you can withdraw at any time without giving any reason.

Is there anything I need to do beforehand?

You should have read this information sheet before the interview and complete the accompanying consent form. If you are unclear on anything, you may contact the researcher at any time (contact details can be found at the end of this leaflet). You will also be given further opportunity to ask questions at the beginning of the interview. If you have not already signed the consent form at the beginning of the interview, you will be asked to do so before the interview can begin.

Is there anything I need to bring with me?

If you have read this information sheet and are satisfied any queries have been addressed, please complete the accompanying consent form and bring with you to the interview. Don't worry though if you are not happy to sign the consent form in advance and wish to ask further questions at the beginning of the interview. Even after you have completed and handed over the consent form, you can still withdraw from the study without having to give any reason.

Expenses and payments

You will not be paid for taking part in this research but if you travel to the University for an interview, the researcher will reimburse you for travel costs (mileage at a rate of 25 pence per mile for car users or reimbursement of public transport costs (not first class) on presentation of appropriate receipts).

What are the possible disadvantages and risks of taking part?

No risks have been identified for this research. However, if you are unhappy with the conduct of the research, you can contact the University to report your concerns. Our complaints procedure details are described at the bottom of this page and overleaf. Again, it should be stressed you can withdraw from the interview at any time without giving a reason.

What are the possible benefits of taking part?

Whilst there is no clinical benefit in taking part, this research will potentially be of benefit to future patients and to NHS organisations. The aim of the research is to develop a practical

understanding of how PPI works, which will help NHS organisations to become even better at engaging with their patients. This will in turn be of benefit to patients and to the public.

What happens when the research stops?

The results of this research will be written up for the purpose of a PhD thesis. The healthcare provider involved in this study will also receive a report detailing the key findings and any recommendations to them. If you would like to be informed about outcomes of the research afterwards, including journal publications, please ensure you give the researcher permission to hold on to your contact details.

What will happen if I don't want to carry on with the study?

If you wish to stop the interview, you can do so at any time without having to give any reason. The interview data will be destroyed and will not be used in the write up of results. However, if you request to withdraw from the study after the interview has taken place, the researcher will review how possible it is to withdraw data collected from you. If write up of results has already begun, it may not be possible to withdraw data. You will be fully informed at the point that you request withdrawal. If you wish to withdraw, you should contact the Main Investigator.

What if there is a problem?

If you are unhappy with the conduct of this study, please contact the research student's Academic Supervisors in the first instance. They will handle any concerns from you. If you are not happy with their response, the University also has a policy relating to Research Misconduct and Whistle Blowing which is available online at [http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm).

If you wish to make a complaint against someone who organised or was involved in a session you attended that the researcher observed, please contact **[insert details of healthcare provider's complaints contact]**.

If you are a patient or carer and have any concerns, you can also contact the **[insert name healthcare provider]**'s Patient Advice & Liaison Service (PALS) team **[insert contact details]**.

If you have been subject to any harm during the research, Loughborough University and the NHS provider both have appropriate indemnity insurance in place to compensate for any harm caused by the neglect of the researcher or NHS staff. If you contact either the University or the NHS provider to make a complaint, the compensation claim process will be explained to you.

Please note that the researcher and their Academic Supervisors cannot address any concerns you have about your personal health and you should contact your doctor or named health professional if you are worried about anything.

Will my taking part in this study be kept confidential?

All information collected from observations of you and interviews you have taken part in will remain anonymous. Recordings and transcripts of observations and interviews will be stored securely on the researcher's computer under password protection. Any quotes that are used in reports and publications will be anonymous and any identifiable information in the quotes (such as names of places) will be removed and replaced with pseudonyms. Nobody will be informed that you have taken part in an interview either. Recordings of interviews will be destroyed once the findings have been written up for the final thesis (due for submission in October 2014). Transcripts will be anonymised using ID numbers and kept on file at the University for 10 years in accordance with their policy relating to research-generated data.

What will happen to the results of the study?

The results of the study will be used to write up a report for the purpose of the PhD and may be used to write up articles for publication about the key findings. A report will also be produced for the healthcare provider, making possible recommendations to help them with future PPI activities. Please note that if you withdraw from the research part-way through, some data may have already been written up and used in reports. If you wish to withdraw, the researcher can advise you whether it is possible to withdraw data previously collected from you.

Who is organising and funding the research?

This study is part of a Student research project supported by Loughborough University. The research student will be undertaking the research (Main Investigator) under the supervision of

their Academic Supervisors, all named above, for the purpose of obtaining a PhD qualification.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the South Central Oxford A Research Ethics Committee. This study has also been reviewed by Loughborough University's Ethics Advisory Committee, as they are the sponsor of this research.

I have some more questions, who should I contact?

The Main Investigator, Sarah Todd, is the main person to address questions to. You can contact them at the address provided at the top of this sheet, or email them at S.A.Todd@lboro.ac.uk. You can also call the researcher on **[phone number]**. If your query is urgent, we would suggest that you call, as the researcher often moves between several sites and so they may not collect post or check email immediately.

If you have more general questions about being involved in research at **[insert healthcare provider's name]**, please contact their Research & Development Lead **[insert contact details]**.