

**EVIDENCING THE VALUE OF PATIENT AND PUBLIC  
INVOLVEMENT IN INTER-ORGANISATIONAL HEALTH  
NETWORKS**

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## **Abstract**

Patient and public involvement (PPI) and inter-organisational networks (IONs) such as the Academic Health Science Network (AHSN) are parallel policy responses to “wicked problems” (Rittel and Weber, 1973, p. 155) in health. The two policy responses have spawned separate literatures with little overlap.

This thesis synthesises the PPI and ION literatures to create a conceptual framework for understanding the context, which an ION provides for PPI. By conceiving of PPI as one form of network-based collaboration, the framework provides a way to understand the structure, functioning, and extent of PPI in an ION. Value can then be evidenced at multiple levels. The thesis uses the conceptual framework to build theoretical propositions that are explored using a single case study design following Yin’s (2014) methodology.

The findings show that public contributors to the AHSN played a range of roles. When health professionals deployed leadership practices in meetings they shared power with the public contributors, giving the public the opportunity to speak. If the public contributors could play a role relevant to the opportunity, then the sharing of power led to the public making a contribution to the meeting. Where the contribution fitted with the style of the meeting, this reinforced trust relationships between professionals and the public. Even the most extensively involved public contributors were outsiders to the organisation, compared with professionals. As outsiders, the public made valuable contributions to the AHSN, in particular challenging it to better implement its stated aims and objectives.

The conclusion argues that effective PPI requires dialogue between professionals and public contributors. Dialogue could be encouraged if network professionals directed their skills at the public as well as at network members. For example, public contributors could be invited to co-create the structure of PPI programmes. Professionals could give public contributors feedback part of the way through the programme. Finally, promoting the range of roles each public contributor can play

would allow the public to create value by encouraging organisations to deliver according to their aims and objectives.

# 1 Introduction

## 1.1 Introduction to the thesis

Patient and public involvement (PPI) and inter-organisational networks (IONs) have been growing features of the English healthcare system. Over the last 25 years PPI in health has been an increasing statutory requirement, motivated at times by increased efficiency, and at others by improved quality (Gibson, Britten and Lynch, 2012). The central idea is that patients should not only exercise choice in their own care, but they should share in decision making at all levels of the English National Health Service (NHS). Over the past 15 years IONs have been seen as part of an NHS modernisation agenda that also includes evidence-based practice, quality improvement, and the diffusion of innovation (Ferlie *et al.*, 2010).

This doctoral thesis formed part of a wider research programme comprising academics with interests in different aspects of the value of IONs. This wider programme examined one of the regional Academic Health Science Networks (called ‘the AHSN’ hereafter), as a case example of a health ION in order to draw lessons on networks and 1) innovation development; 2) innovation diffusion and; 3) in this thesis, PPI. This chapter details the wider research programme before introducing the government aims associated with each of PPI and AHSNs. The next section sets out the case studied in the thesis: the PPI programme at the AHSN. The initial, tentative research questions are listed next. Then there is a section to introduce the researcher. As is customary in PPI, this research not only studied involvement but practised it as well. A public adviser worked with the researcher throughout the three-year doctoral journey, and that role is described next. In line with the reflective nature of these two sections they are the only parts of the thesis written in the first person. The final section sets out the structure of the remaining thesis, chapter by chapter.

The many abbreviations used in the NHS are explained the first time they are used, and also appear in Appendix 1. Appendix 2 provides a glossary of the important terms used throughout the thesis.

## 1.2 The wider study

The AHSN commissioned the wider study, of which this thesis forms a part, from a group of universities. The three strands of the wider study comprised: developing innovation in whole networks, diffusing innovation, and PPI (this study). The wider study shaped the thesis title, *evidencing the value of PPI at an inter-organisational health network*. Once case study methodology had been selected for this doctoral thesis, the academics from the other strands of the wider study also chose it. The entire team debated the proposal made for this thesis that the AHSN should be the case, and the projects through which the AHSN operated should form the “embedded units” (Yin, 2014, p. 55). The final agreement to the proposal acknowledged the multi-organisation projects as the vehicles for the AHSN’s work and as the best way to examine the operational detail of each of innovation development, innovation diffusion and PPI. Retaining the AHSN as the case allowed the final report to draw the various research strands together and the academics to generalise their findings beyond the immediate AHSN, to other IONs in health and public services.

The AHSN asked the entire research team to co-ordinate and compromise in only one area: the choice of projects to study. All the researchers agreed not to overwhelm any single project or staff member with multiple parallel data collection activities. In effect, this meant that the researchers chose different projects for their strands depending on whether the project focussed on developing innovation, diffusing innovation and whether the public were involved. The selection of case study methodology for this research, and the subsequent agreements with the other academics, thus defined the study of PPI at the AHSN as the case, and the projects using PPI as the embedded units. The wider research study did not affect the selection of epistemology, or other elements of the research design. The otherwise loose relationship between this doctoral thesis and the wider research study entailed providing quarterly progress updates for the wider team, exploring common themes as they emerged from each separate area of study, and contributing to the final report.

### **1.3 Introduction to PPI**

This research examines PPI in an ION, using the AHSN as the particular case. The term ‘PPI’ has been used in this study primarily because it was the one used by the AHSN. The AHSN called the members of the public who became involved ‘public contributors’ so this phrase is used throughout the thesis. The UK government’s commitment to PPI in the English NHS, expressed in recent documents as “no decision about me, without me,” (Department of Health, 2012, p. 1), extended beyond patient choice and partnering in self-care to “widespread adoption of shared decision-making” (Department of Health, 2012, p. 1). The expectation cut across not just the service element of health but also into other domains such as commissioning (see Evans *et al.*, 2013) and especially research. For example, the National Institute for Health Research (NIHR), reviewed grant applicants’ plans for involving the public as part of the approval process (INVOLVE, 2012).

### **1.4 Introduction to the AHSN**

The AHSN was set up in 2013 and was one of 15 regional AHSNs with a five-year licence from the English NHS. The AHSNs had four core objectives: -

- “1. Focus on the needs of patients and local populations: support and work in partnership with commissioners and public health bodies to identify and address unmet medical needs, whilst promoting health equality and best practice.
2. Build a culture of partnership and collaboration: promote inclusivity, partnership and collaboration to consider and address local, regional and national priorities.
3. Speed up adoption of innovation into practice to improve clinical outcomes and patient experience – support the identification and more rapid spread of research and innovation at pace and scale to improve patient care and local population health.
4. Create wealth through co-development, testing, evaluation and early adoption and spread of new products and services.” (NHS England, 2015)

The AHSN acted as the central, organising body for formal, fee-paying members from across seven different council boundaries [AHSN, 2016a]. The members were 15 NHS and social care providers, seven commissioning bodies, and three universities [AHSN, 2016b]. Thus the network was of significant scale, and the members far from homogeneous, although they all had an interest in health and

social care services or research. Representatives from each member organisation sat on the AHSN's board, its governing body [AHSN, 2016c].

The AHSN administered the network, and was accountable for achieving the collective, government-set objectives through initiating and running individual projects. Each member organisation had its own, additional set of aims and objectives. These characteristics of the AHSN mean it can be categorised according to well-understood typologies from the ION literature as a mandated "Network Administrative Organisation" or NAO (Provan and Kenis, 2008, p. 236). The categorisation is a good fit for the AHSN, has been widely adopted by other scholars and allows the thesis to draw generalisable lessons for other mandated NAOs in health and other areas of the public sector.

With its members, the AHSN collaborated in four key work areas: working with industry (department 1), avoiding unnecessary harm to patients (department 2), quality improvement (department 3), and the way data can support decision-making (department 4). The collaboration, and the majority of the AHSN's work, took place in projects set up and run within each of the four departments. First, the AHSN's board would approve a project as a piece of work that fit with the AHSN's remit and as a priority area for its member organisations. Next, the AHSN would invite the members to provide staff to be part of a project team. Although the AHSN had a mandate from government, its structure as an NAO formed of members with their own objectives meant attracting support from members by starting projects that would help progress the members' own interests. The AHSN's five-year licence term served to focus minds on remaining relevant to the member organisations even in the face of shake-ups such as the sustainability and transformation partnerships (NHS, 2018) in order to influence the renewal of the licence for a further term

### **1.5 The PPI programme at the AHSN**

The AHSN operated directly in neither health research nor health services, but had member organisations in both areas. The AHSN and its members staffed projects, some of which addressed specific health conditions, but many of which did not. While not a specific objective or work area, PPI formed one of the collaborative

working methods used by the AHSN to meet its government-set objectives and represented an area of specific focus for the organisation. The AHSN’s PPI Manager administered the PPI programme, which included organising the recruitment and selection of the public contributors, assigning them to projects, negotiating their attendance, dealing with their expenses, and promoting PPI within the AHSN. 12 public contributors were involved at the AHSN for two-year terms. Two of these public contributors attended AHSN board meetings. All 12 were deployed in pairs to work on projects, as shown in Figure 1.1 below. The projects tackled subjects often not directly relevant to the public contributors’ own experience as either patients or carers. None of the public contributors joined the AHSN as formal representatives of any charities or patient groups.

**Figure 1.1 The structure of PPI at the AHSN**

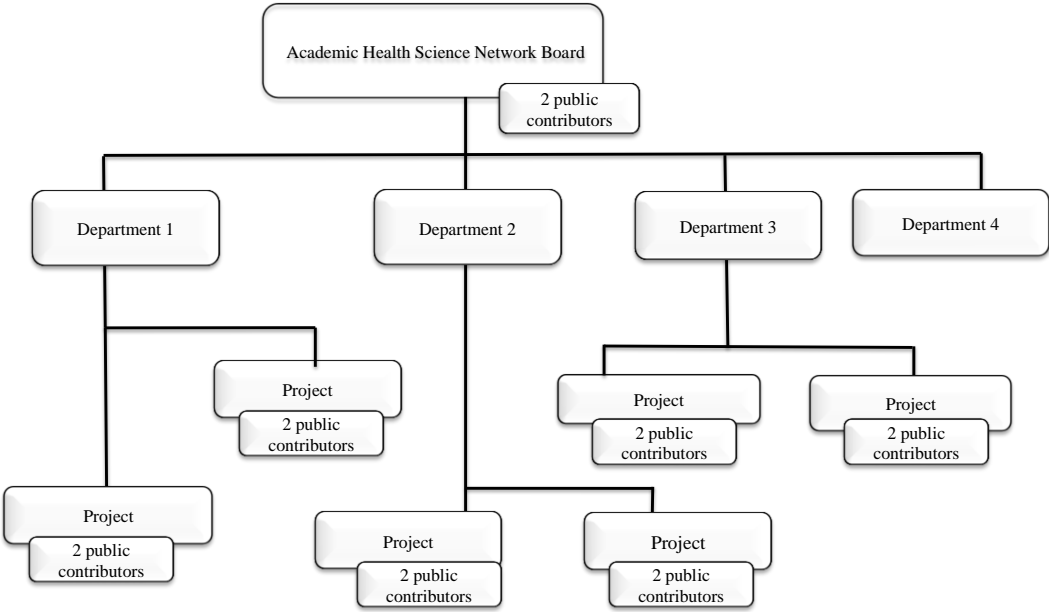


Figure 1.1 is adapted from internal material produced by the AHSN [AHSN, 2015], and is adapted and reproduced in an anonymised form with their permission.

The AHSN was also part of a specific collaborative partnership with three other organisations that aimed to promote “innovative and effective PPI” [PPI Partnership, 2015, p. 2] in health research and service improvement. It joined these three local organisations and invited public contributors to produce a PPI strategy that committed the four partners to: coordination; capacity and capability building;

evidence building and sharing; influence of policy and practice; and engagement of a wider public [PPI Partnership, 2015]. PPI staff were employed by each of the member organisations, but located together [PPI Partnership, 2015]. For example, the AHSN's PPI Manager sat with the AHSN staff for part of the working week, and with PPI staff from the other partners for the rest of the week. Thus the AHSN not only practised PPI, but also joined other organisations to promote and encourage the adoption of PPI.

## **1.6 Initial research questions**

The initial, over-arching research question for this doctoral thesis was, *to what extent does a network organisation form support successful public involvement?* Here, the AHSN is regarded as the specific case for drawing out conclusions relevant to other mandated NAOs in the public sector. The following sub-questions followed on: -

1. *To what extent can public contributors be regarded as part of an inter-organisational health network?*
2. *What factors are associated with successful PPI?*
3. *Which characteristics of inter-organisational health networks have the potential to promote PPI?*
4. *To what extent do inter-organisational health networks deploy successful network behaviours to involve the public?*
5. *What impact has PPI had in inter-organisational health networks and the wider networks?*

## **1.7 Introduction to the researcher**

Researchers are encouraged to introduce themselves in PPI because involvement includes “the issue of identity in discussion rather than taking it as given”



(Beresford, 2013, p. 141). Unusually amongst PPI researchers, I had no professional or personal commitment to PPI. Many others do. For example, Turner's (2010) thesis drew on a background as a PPI manager. Crepaz-Keay (2014) brought experience as a mental health service user. Some, PPI researchers such as Beresford (2013) combine an academic interest, experience as a service user and activism.

While not objective, I am an outsider to PPI. With an interest in collaboration developed over many years in procurement and supply chain jobs, I have developed a view of PPI as one form of collaboration, taking place here in an ION. This view is an unusual one in PPI research, and I hope it means I add something new to the debate about the value of PPI.

In the absence of direct experience, Corbin and Strauss (2008) urged researchers to develop their sensitivity by finding an experience that is close enough to develop insight into their subject. During my first 18 months as a doctoral student I volunteered to be a post-graduate student representative on a university committee. I had decided to volunteer as part of an effort to be a good university citizen, but before I began, it occurred to me that it had some similarities with the role of public contributor to a health organisation. I was an outsider to the university committee of staff. I was invited purely because I was a doctoral student. I was there to be a student voice, yet there was no sense in which I represented my fellows: I was not elected, I was barely connected to the rest of the student body, and I was too old, too white and too wealthy to be regarded as typical.

Forty-eight hours before my first meeting, the papers had not yet been distributed to the two student members, so I asked for and received them with apologies. On arriving at my first committee meeting, the members of staff already present looked up and then immediately continued their conversation. It was five minutes until they finished and introduced themselves. When it transpired that I hadn't read all the papers, the permanent staff member did not confess that the students had been left off the email distribution. The other student representative and I were asked to leave the room after the first hour. The meeting continued without us to cover material of a confidential nature. None of the committee members had bothered to discover my 20 years of history keeping managerial and personnel information

confidential. Any glance through the PPI literature will reveal the parallels between student committee representatives and public contribution at a health organisation.

### **1.8 The public adviser**

Involvement research typically seeks to practise what it preaches. This study is no different. I met the public adviser to my thesis, John (a pseudonym), at an involvement journal club run by the university where I am enrolled. I invited him out to coffee to discuss the possibility of working together for the next three years. Together we crafted a role description (see Appendix 3). In line with best practice the involvement here has been from the beginning, throughout the process and at regular intervals. John has been the ultimate PPI insider to my outsider. A public contributor to the AHSN for the first year of this study, a former member of his general practitioner's (GP's) patient participation group (PPG), the instigator of an applied health research project, and a National Institute for Health and Care Excellence (NICE) lay adviser, John has been able to review my plans, read my work, and make suggestions all from the perspective of an experienced public contributor.

John's review of my participant information and consent forms appears to have helped this study's progress through the ethics process. His proof reading skills have improved the standard of the thesis text. His wide reading and subsequent recommendations have expanded the reference list. His questions have prompted me to re-visit my understanding. A formal review of the public involvement in this doctoral research is provided in Appendix 3 using the Guidance for Reporting Involvement of Patients and the Public 2 Short-Form (GRIPP2-SF) approach (Staniszewska *et al.*, 2017).

While John and I have written a joint blog about the experience of public involvement in the doctorate, one frustration of the limitations of the doctoral process is that I must speak for John in the thesis, causing him to merely review this section, rather than writing it with me.

## **1.9 Structure of the thesis**

This section sets out the structure of the remaining thesis chapter by chapter, highlighting the part played by each in evidencing the value of PPI at the AHSN. In particular, this section shows how the thesis develops, uses and then refines a conceptual framework drawn from the PPI and ION literatures.

Chapter two, the literature review, begins by outlining the critical realist review approach to the search for and selection of material. It then reviews and constructs definitions for key terms. It establishes both PPI and IONs as parallel policy responses to particularly difficult problems in health. The two policy responses have spawned separate literatures with little overlap. However, if IONs are deconstructed into different levels then they can be viewed as networks of individuals, some of whom belong to the same organisations. In this way, PPI can be seen as one specific form of network-based collaboration between individuals, some of whom are clustered together in organisations. This synthesis of the PPI and ION literatures allows the creation of a new conceptual framework to study PPI at the AHSN. This framework uses the ION literature to categorise the network as a specific context for PPI. The framework employs variables from the PPI literature to describe the structure of PPI, in other words, to understand who is being involved and how. Functional variables that resonated in both sets of literatures describe how PPI programmes operate. Social Network Analysis (SNA), mapping the strength and frequency of connections between professionals and public contributors, details the extent of the resulting involvement. The value of the PPI can be evidenced at multiple levels (individual, client, community, organisation and network) as the effects the public contributors had on the work with which they became involved. Finally, the research questions are revised in the light of the conceptual framework.

Chapter three, the methodology, details the use of critical realism as the ontology in this case study research. Yin's (2014) methodology guided the research design, a single case (PPI at the AHSN) with multiple embedded units (three projects each involving public contributors). Theoretical propositions, drawn from the conceptual framework, linked to each research question, guide the enquiry. The chapter shows how the research design attempted to build quality into the study through

triangulation between multiple sources, a chain of evidence, the use of theoretical propositions, of an auditable case database, the consideration of other explanations, and review by the public adviser. The ethics section describes the steps taken to protect the confidentiality and anonymity of the 25 professional and public contributor participants. Data from documents, observations and interviews were coded and analysed using codes drawn from the conceptual framework.

Chapter four, the findings, sets out the evidence from the case according to the conceptual framework developed in the literature review. The ION context of the PPI is explored. The structural variables describing the framework of rules and guidelines governing PPI at the AHSN are broken into those that applied to the PPI programme as a whole and those that applied to each of the three different projects studied. Then the functional variables show how PPI at the AHSN actually operated within its structure. The evidence collected under the codes for aims and objectives, legitimacy, leadership, power and trust is presented in turn. A network map, drawn from answers to a network survey conducted as part of the interviews, is set out for each project and shows the extent to which the public were involved in the work alongside professionals at the AHSN. Finally, the value attributable to PPI is presented using the verifiable effects from public contribution in each of the three projects studied.

Chapter five, the discussion, considers the findings in the light of the debates in the PPI and ION literatures. The chapter shows where the theoretical propositions have been supported, refuted or refined by the evidence. The direct impact of the wider network context on the PPI programme at the AHSN is detailed. Six structural variables are added in order to provide a more complete description of the programme. In addition to showing how the functional variables describe the operation of PPI at the AHSN, the chapter shows how legitimacy, leadership, power and trust link to each other. The network maps are presented as a way to assess the extent of the public involvement. The value of PPI is evidenced using triangulated data on the effects the public contributors had at the individual, client, organisational and network levels. The value from the public contribution derives primarily from the public contributors playing a range of roles to challenge the

AHSN to implement its own stated aims and objectives more effectively. Finally, the chapter adapts the conceptual framework in the light of the findings.

Chapter, six, the conclusion, formally answers each research question. The chapter also details the limitations of this single-case study design before exploring the study's contribution to theory. The final sections set out recommendations for practice and for future research before making concluding remarks.

## **2 Literature review**

### **2.1 Introduction**

This chapter uses critical realist review to bring two separate literatures together into a new synthesis. As neither the PPI nor the ION literatures contained primary evidence in directly relevant circumstances, this chapter focuses on identifying conceptual variables that affect collaboration. Each section of the chapter builds these conceptual variables into an original framework, which serves as a tool for analysing PPI at in ION.

The conceptual framework conceives PPI and IONs as parallel responses to health-based “wicked problems” (Rittel and Weber, 1973, p. 155). The use of the key terms in the literature is explored in order to adopt definitions that can be used consistently. The framework shows that the two policy responses have spawned separate literatures with little overlap. The chapter therefore reviews each literature in turn for those conceptual variables that could be useful for considering collaboration between individuals in an ION setting. The conceptual variables are split into structural, which capture the formal organisational intent of the PPI, and the functional, which capture the practice of PPI. Each of the two literatures has internal limitations that must be overcome before the variables can be synthesised into a single framework for use in studying PPI in an ION.

The conceptual framework bridges the gap between the two literatures by breaking IONs into their constituent levels of individuals, work groups, organisations and whole networks. The chapter sets out an argument for using mixed units of analysis within the same network. PPI is considered as a collaboration between individuals some of whom are clustered together in organisations. This approach means that SNA can be used to map the connections between the individuals collaborating as part of a PPI programme. It also means that PPI can be seen as one particular form of ION-based collaboration.

Once the gap between the literatures has been bridged, this chapter sets out the final piece of the conceptual framework. The ION literature is used to categorise the

organisational context for PPI. The conceptual variables are grouped into structural variables, which describe the approach to PPI, and functional variables, which describe how the PPI works in practice. SNA is used to capture the extent of the involvement by mapping the existence, strength, and frequency of connections built up between professionals and public contributors. Evidence for the value of PPI in an ION is then sought at multiple levels, from the individual to the network. In the final section, the conceptual framework is used to revise the original research questions.

## **2.2 A critical realist review of the literature**

The key challenge for this chapter lies in bringing together two extensive literatures: on PPI and on IONs. Scoping each literature using recent systematic and structured reviews provided an understanding of its state, development, and key debates. This initial scoping also provided the first indication that the ION and PPI literatures rarely overlapped. The literature review approach thus changed from the initial conception of a systematic search for other PPI studies that had taken place in IONs and had taken cognisance of the ION as the context. Instead, the chapter approached the literatures using “critical review” (Grant and Booth, 2009, p. 93).

Critical review was one of 14 types of review identified in Grant and Booth’s (2009) typology of literature reviews. As well as incorporating extensive research and critical evaluation of literatures, the authors characterised critical review as the analysis and synthesis of disparate papers. From the synthesis, a new model or hypothesis emerges. Because critical reviews did not exhibit a systematic approach, and the interpretations were subjective, their value was based on the concepts produced. Consequently, critical review produces concepts requiring evaluation and testing rather than authoritative statements on the state of the existing evidence.

Critical review has been further developed as a specifically realist approach (Edgley *et al.*, 2016). A review becomes a “critical realist review” (Edgley *et al.*, 2016, p. 316) when the subject of the study is structures, or characteristics that are not necessarily empirically observable, and may not be actual (that is, realised), but are nonetheless real. Edgley *et al.* (2016) described an approach designed to bring about

new theories or develop existing ones. As well as fitting with the critical realist ontology of this thesis (see Chapter Three, Section 3.2), the critical realist review was appropriate because of its focus on bringing together two separate literatures. The subject of the study became the concepts used in the PPI and ION literatures, rather than a review of a primary evidence base.

While eschewing a fixed recipe for how to do critical realist reviews, Edgley *et al.* (2016) provided guidance on the approach, which has been applied to this review. The central focus was to study other people's ideas about PPI and IONs in order to look for concepts that appeared in both literatures, or were missing in one or the other. The initial questions (from Chapter 1, section 1.6) were considered as starting points, to be refined in the light of the review. Some specific database searches of the academic literature were made and these are set out in Appendix 4. However, rather than strict inclusion and exclusion criteria, the review sought to be open to sources that contained valuable ideas, including practice-based material.

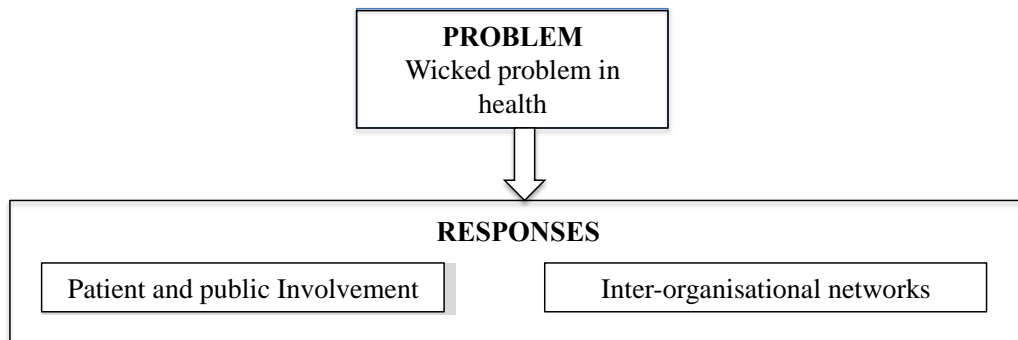
Edgley *et al.* (2016) claimed that a critical realist review is never partial. However, the experience of this review supported Grant and Booth's (2009) views of the limitations. Without a precise question and strict criteria, a search cannot claim to be comprehensive. The ION and PPI literatures may have contained useful concepts that were overlooked here. However, the strengths of a critical realist review are not objectivity or a systematic approach. The strengths of a critical realist review lie in the extent to which the ideas are developed into an argument that casts new light on a phenomenon.

### **2.3 Terminology and definitions**

Wicked health problems have two separate policy responses that concerned this thesis: PPI and IONs. Figure 2.1 shows this conception as the first section of the framework being built here. Before progressing further, each of the terms in Figure 2.1 is examined and defined. There were two reasons for an early focus on definitions. The first was to aid readers from different traditions. The second was to fit with the critical realist ontology described in Chapter 3, Section 3.2.



**Figure 2.1 The first section of the framework**



### **2.3.1 Definition of wicked problems**

Rittel and Weber (1973) first used the term wicked problems and set out their characteristics which are summarised here. A problem is wicked when describing it means already having ideas on its solution. For example, unmet health needs could be described as needs that healthcare providers cannot afford to meet (in which case the solution involves increased spending); or as needs which have not been articulated (in which case marginalised groups might require assistance with language or advocacy). Because descriptions of wicked problems always imply what the solution should be, the complete solution set is impossible to generate. There is no way to know when to stop addressing wicked problems. For example, there is no way to know when or if unmet health needs have been extirpated. Attempts to address unmet health needs may cease if time or money runs out, rather than because the best solution has been identified, used, and found to work. Wicked problems do not have solutions that all stakeholders agree on. Perspectives differ. The intended solutions to wicked problems cannot be tested, either immediately or over time because in an open, inter-connected system, the solutions will create unintended consequences over an almost indefinite period. Consequently, definitive evaluation of intended solutions is impossible. The proposed solutions to wicked problems are typically resource intensive, not easily reversed, and impact the lives of many people. This means that there is no opportunity to learn through trial and error or to be wrong. Wicked problems are both unique and likely to be symptoms of other wicked problems. For example, unmet health needs can be seen as a symptom of poverty. Thus the unmet health needs could not be resolved without

tackling the poverty, something health care providers seem to have neither the resources nor the remit to undertake.

### **2.3.2 Definition of PPI**

In order to explore and define the terminology of PPI this section draws from publications in health research and health services. Most studies have been written exclusively in one or the other. For example, Brett *et al.* (2014), Staley (2009) and Evans *et al.* (2014) were all based exclusively in health and social care research whereas Mockford *et al.* (2012) reviewed PPI in papers on health and social care services. There were three reasons for drawing from both here. First, the findings were remarkably similar. This was despite the wide acknowledgement that PPI is highly context specific (Evans *et al.*, 2014 and Staley, 2009). Second, IONs, by design, span across discipline boundaries so both were relevant. Third, the intent of this critical realist review was to be open to ideas from different traditions.

PPI literature reviews (Brett *et al.*, 2014; Staley, 2009; Mockford *et al.*, 2012; and Conklin, Morris, and Nolte, 2012) have lamented the absence of common terms and definitions, which made comparison difficult. These literature reviews also found that most studies did not define their terms at the start. A systematic review of PPI in papers from 1997 to 2009 and covering 28 studies found that many gave only “broad indications” (Mockford *et al.*, 2012, p. 35) of what was meant, rather than rigorous definitions. Conklin, Morris and Nolte (2012) complained further of terminology changing within studies.

In the literature, each of the words in the phrase ‘patient and public involvement’ had a range of loose synonyms that it is worth examining. Patients could be described as service users, clients, consumers, partners, and participants. The public could be carers, citizens, lay people, family members, and stakeholders.

Involvement could be participation, engagement, collaboration, co-production, consultation, evaluation, partnership, and emancipation. Studies that used the same wording were not necessarily describing similar approaches, while studies that used different wording might be (Rowe and Frewer, 2005).

As a further complication, some authors have seen the public themselves as increasingly diverse, and so addressing wicked problems becomes harder because there is no single public interest (Rittel and Weber, 1973). Increasing diversity has been seen as a driver for including the public in devising the responses to wicked problems. Authors from the deliberative democracy tradition in particular made this connection (see Raisio and Vartiainen, 2015). Indeed, direct citizen participation was seen as the only approach to wicked problems by a “growing number of social scientists” (Roberts, 2004, p. 340).

From this picture it is clear that future studies, including this one, must choose terms wisely, use them consistently throughout, and the definitions must fully explain what is happening. One paper suggested that the public is “constructed” (Braun and Schultz, 2010, p. 408) according to what it has been invited to take part in. Therefore, the ‘involvement’ helps to define the ‘patients and public’ and the two must be explored together. In order to make progress, this study took as its starting point definitions from INVOLVE (a part of the NIHR dedicated to nurturing public involvement in health and social care research).

INVOLVE defined the public as “patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services” (INVOLVE, 2015). The key group implicitly excluded from this definition was current health-sector professionals. For the purposes of this thesis, a professional was anyone assigned to a project as a result of their paid employment. The INVOLVE definition of the public presented this thesis with a problem by describing the public exclusively in relation to patients. That is, either directly or indirectly as carers of patients, as future patients, or as representatives of patients. The closest the definition comes to admitting the general citizen (with no relevant experience as patient, carer or service user) is as a potential future patient. People from voluntary organisations are admitted, but only so far as they represent patients.

INVOLVE’s definition of involvement in research was given as “research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them” (INVOLVE, 2015, emphasis in original). In research terms this meant that it

was not involvement if the public were only the research subjects (for INVOLVE this was participation), or if the public only had information provided to them (this was engagement). The distinction between involvement, engagement and participation is important. Participation is the simplest. In this doctoral research, participation is used in the way INVOLVE (2015) employed it, to mean inclusion in research as one of the subjects. Thus the interviewees and the individuals observed in this thesis were participants, and their role is described as participation. The terms involvement and engagement, both required further input in order to widen their definitions beyond research.

Braun and Schultz's (2010) typology was used to examine and evaluate the INVOLVE definitions. The typology described four types of public: "the general public, the pure public, the affected public, [and] the partisan public" (Braun and Schultz, 2010, p. 408). The term general public tended to be used when surveys and opinion polls aimed to discover a general state of understanding, views or opinions. If the views were sought for research purposes, then this could be participation in INVOLVE's (2015) terms. However, when the general public's opinion was sought for purposes other than research, this thesis defined the activity as engagement. The term engagement also covers education, information or conference materials being pushed at the pure (or as yet uneducated) public to discover what worked. Of course, if the public had been invited to review, shape or co-create the materials for such education, then this part of the work would count as involvement.

The affected public (Braun and Schultz, 2010) was more problematic. The affected public could be invited to a range of activities, only some of which were involvement. If the affected public was a patient deciding aspects of their own health care, then this was not involvement. If the same affected public became subjects in research into their condition, then this was participation. If, on the other hand, the affected public helped researchers to determine the research aims, process, and outputs, then this was involvement. However, this thesis wanted to admit into involvement a wider public than just the affected.

The partisan public was also problematic. Where special interest groups contributed to policy discussions, this was called lobbying and was not seen as a form of

involvement in this thesis. The INVOLVE definition of the public specifically includes organisations which represent the views of service users but in this thesis the partisan public take part in lobbying and do not fall within the definition of PPI.

As none of Braun and Schultz's (2010) constructions of the public exactly suited this study, the deliberative democracy tradition was examined, especially with regard to its use of the term citizen. Roberts (2004) expanded the definition of the term citizen so that it encompassed not only the legal meaning but also elements of community, duty, civility and moral values. Roberts said, "this perspective on citizenship requires both collective and individual virtue and moral purpose. Its scope is broader than the legal definitions and it extends not only to formal government arrangements, but it also includes voluntary organisations and community involvement" (Roberts, 2004, p. 319). While this construction of the citizen was helpful, the deliberative democracy tradition concerned a form of collaboration, which is distinct from the involvement considered here.

The emphasis in deliberative democracy was on open dialogue, on diverse opinions being shared, understood and ultimately, on changing minds so that fair, legitimate decisions could be reached (Blacksher, 2013). The key differences when compared with involvement were the numbers of citizens invited to the collaboration and the extent to which the deliberations were conducted in public. Although there was a conception of single individuals practising "citizen behaviour" (Vigoda and Golembiewski, 2001, p. 274) it was by employees and occurred only in their workplaces.

Using INVOLVE's definition as a base, but constructing the public by building in conceptions of the citizen, the definitions adopted in this thesis are as follows. Patients and the public are defined as patients, carers and people who use health and social care services as well as other individual citizens, excluding health sector professionals and those employed by the involving organisation. Involvement is defined as healthcare projects being carried out in an organisation '**with**' or '**by**' patients and the public rather than '**to**', '**about**' or '**for**' them. Those patients and the public who are involved according to this definition are called public contributors. Any criticism, suggestion, comment, or action made by a public

contributor is called a contribution. By contrast to involvement, engagement in this thesis covers circumstances where materials or education are aimed at the public, or where the opinions or views of the public are sought. Those at whom engagement is aimed are termed the general public.

The definitions of patients and the public and of involvement have required considerable adjustment from what already existed in the PPI literature. Concepts have been introduced and adapted from other traditions such as deliberative democracy. This difficulty with the definitions illustrates that the nature of the PPI studied in this thesis differed along several dimensions from that covered by the health research and services literature.

### **2.3.3 Definition of IONs**

The definition of wicked problems included an understanding of them as interconnected, and as occurring in an open system or a “systemic network” (Rittel and Weber, 1973, p. 156). Given this, it was unsurprising to find that one of the ways to respond to wicked problems was by forming inter-connected networks of public sector organisations (Weber and Khademian, 2008; Jackson and Stainsby, 2010; Ferlie *et al.*, 2011). The advantages of a networked response were suggested as being that inter-connected problems could not be adequately tackled by single public sector organisations working alone (Ferlie *et al.*, 2011), and that networks were particularly suited to uncertainty, conflict, and complex problems that spill over the remits, regions and structures of public sector organisations (Weber and Khademian, 2008). In order to explore the use of IONs in tackling wicked problems, networks are defined here, first as an organisational form, and then as a unit of analysis for study.

An early definition of strategic networks was “long-term, purposeful arrangements among distinct but related for-profit organisations that allow those firms in them to gain or sustain competitive advantage vis-à-vis their competitors outside the network” (Jarillo, 1988, p. 32). Jarillo’s definition makes it clear that a network can be planned and managed. In their study of English healthcare networks, Knight and Harland (2005) suggested that network management was possible, as long as

managing means shaping and organising a network. Jarillo's definition also shows that a network is formed around a goal. For a health network, the goal is not competitive advantage as it would be in a for-profit firm. A specifically public-sector definition of strategic networks is "groups of three or more legally autonomous organisations that work together to achieve not only their own goals but also a collective goal" (Provan and Kenis, 2008, p. 231). While useful, this definition represents only one aspect of the way networks are viewed in this thesis.

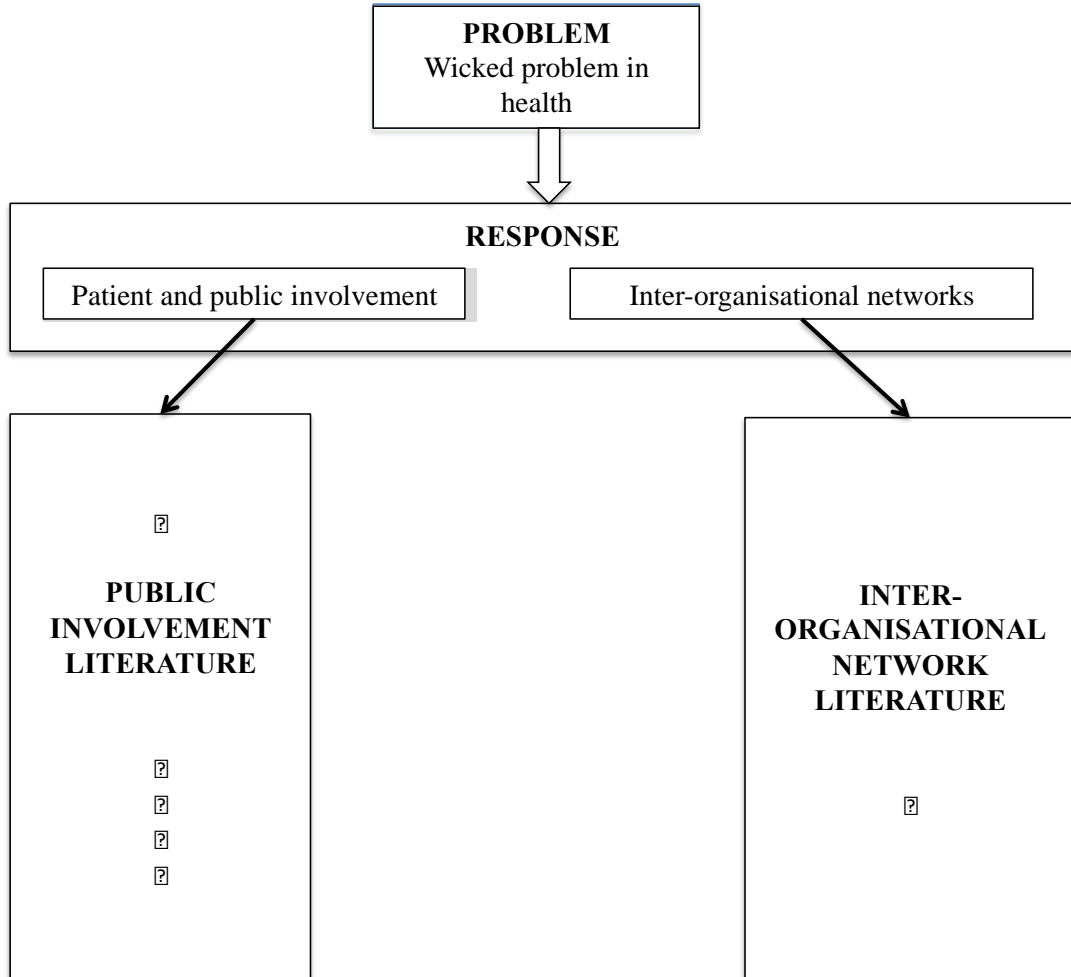
The ION literature divides between those who use networks as an organisation form (as above), and those who employ networks as a unit of analysis for which the constituent parts of the network must be established (Knight, 2002). As well as the central organisational form of the network this study also used networks as a unit of analysis. Used in this sense, a network comprises "actors" (Conway and Steward, 1998, p. 233), sometimes called nodes in a network, which can be individuals, groups or organisations. Between the actors are "links" (Conway and Steward, 1998, p. 234), which characterise the type of relationship in terms of formality, intensity and reciprocity. Finally, "flow" (Conway and Steward, 1998, p. 235) characterises the content of the relationship in terms of information, money for goods and services, or friendship. Networks tend to be analysed using a consistent actor type throughout. Typically, the network is of individuals or work units or organisations. When using networks as a unit of analysis, researchers must define its boundaries (Knight and Harland, 2005). Even in attempts to study whole networks, analysis is really of a partial network (Conway and Steward, 1998; Bidart and Charbonneau, 2011) where the researcher has decided what qualifies an actor to be considered part of the network.

This thesis follows Provan and Kenis (2008) in defining the ION as the organisation implementing PPI plus its autonomous, formal members. The organisation implementing PPI has been set objectives by government that can only be achieved by collaborating with its members. The members retain additional, individual objectives as well. This thesis also uses the network as a unit of analysis where the actors, links and flow have yet to be established. In particular, for use in evidencing the value of PPI in an ION, the definition does not yet include a conception of how an individual citizen could be part of an ION.

## 2.4 Drawing concepts from the PPI and ION literatures

The parallel responses of PPI and IONs to wicked problems have spawned separate literatures, as shown in Figure 2.2.

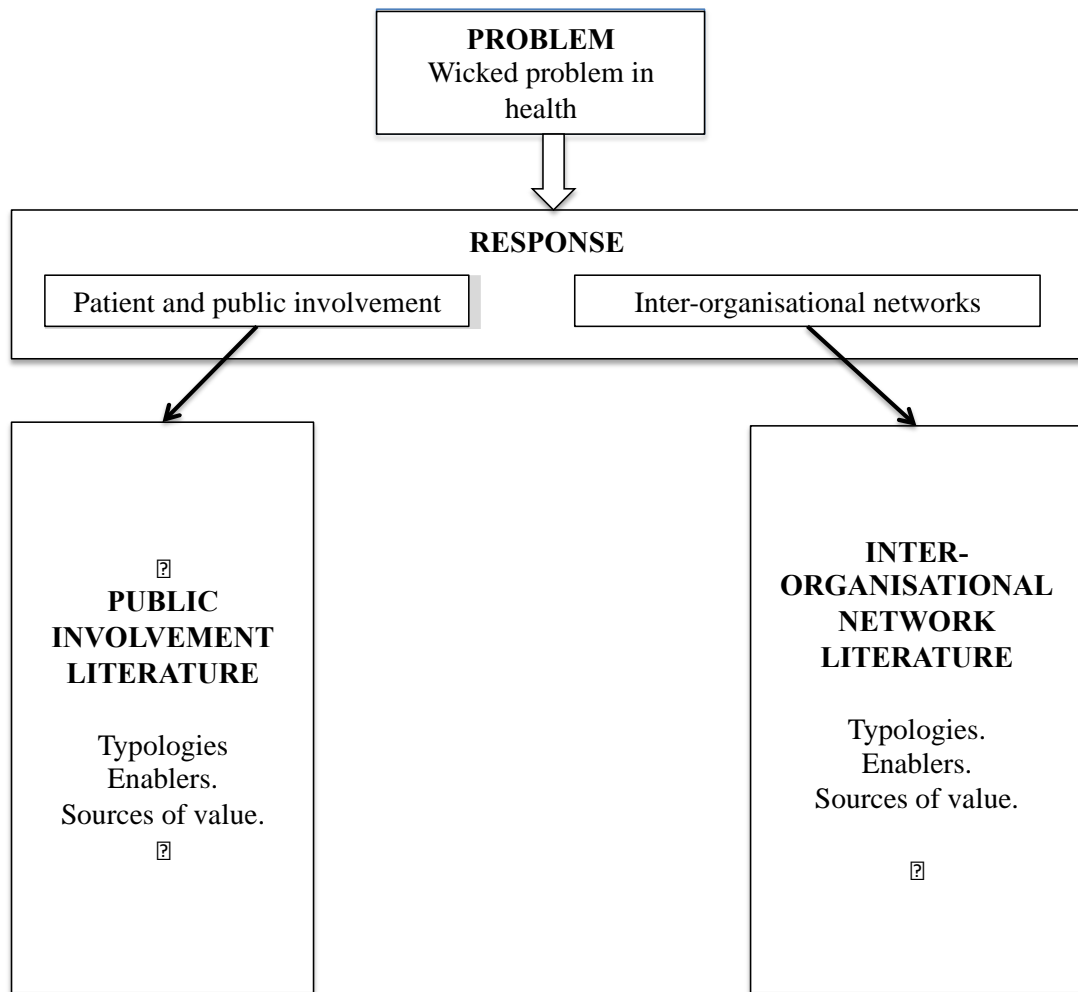
**Figure 2.2 The separate literatures of PPI and IONs.**



In this section, the PPI and ION literatures are examined separately as sources of useful concepts (see Figure 2.3), even though it is not yet clear how these concepts could be considered in a way that spans between individual public contributors and a network of organisations.



**Figure 2.3 The sources of useful concepts from the literatures**



#### **2.4.1 Typologies in the PPI literature**

In their literature review of PPI in health services, Mockford *et al.*, (2012) found that only two out of 42 papers reviewed were underpinned by theory, and even then neither was a theory of involvement. Papers that present a theoretical analysis of involvement often begin with typologies (for example, Cornwall, 2008; Gibson, Britten and Lynch, 2012; Blacksher, 2013). Typologies represent an attempt to identify “conceptually significant variables” useful to “predict or describe” (Rowe and Frewer, 2005, p. 252) effective involvement. Typologies may also provide the variables with which to construct meaningful explanations of involvement. The typologies in this section are drawn from several different fields: planning (Arnstein, 1969), overseas development (Farrington and Bebbington, 1993; Pretty, 1995; White, 1996), health and social care research and services (Oliver et al, 2008; and Gibson, Britten and Lynch, 2012) and public engagement in science (Rowe and

Frewer, 2005). Because the typologies tend to be generalised, they admit PPI as it has been defined for this thesis. The ones chosen here either identify variables or refine or extend the use of already identified variables.

Arnstein's ladder (1969) has been the starting point for many in discussions of the theory of involvement (Cornwall, 2008; Oliver et al., 2008; Gibson, Britten and Lynch, 2012). The ladder led from forms of "non-participation" (such as "manipulation" and "therapy"), through "tokenism" ("informing", "consulting" and "placating"), to "citizen power" (first in partnership and then *in toto*) (Arnstein, 1969, p. 217). It denoted progress upwards from bad forms of involvement to better ones and illustrated that much of what purported to promote citizen involvement did nothing of the sort. For Gibson, Britten and Lynch (2012) its use was to focus discussion onto power, specifically the power to make decisions (Blacksher, 2013). At the top of the ladder, the citizen, not the organisation, has initiated the involvement programme. Pretty's (1995) typology has a similar summit, "self-mobilization [sic]" (Pretty, 1995, p. 1252), where the public invited organisations to the discussion in order to make use of their expertise and resources. Thus the variables captured are power (especially over decisions) and who initiates the involvement.

As well as ladders, the literature contained matrices to account for involvement along multiple dimensions. Farrington and Bebbington's (1993) two-by-two matrix plotted the "depth of interaction" from "shallow" to "profound" (Farrington and Bebbington, 1993, p. 104) and the "scope of the subject matter" from "narrow" to "wide" (Farrington and Bebbington, 1993, p. 104). These concepts appear useful. If the public is only shallowly involved in projects with narrow scopes then the potential value may be limited by design. However, operationalising these concepts appears to be a challenge. Within the same context, the scope and depth of projects can be judged comparatively, but it may be much more difficult to judge across contexts.

White (1996) mapped the interests of both the public and the organisations when involvement happened, and captured the form and function of each involvement type. The organisation and the public have different interests, and involvement (or

participation in White's terminology) had at least four possible aims, "display", "means", "voice" and "means/end" (White, 1996, p. 10). White (1996) also extended the model in an attempt to capture the dynamics of change over time, and the struggle within each set of interests, between the sets of interests and with outside interests. Thus from White's (1996) typology the variables captured are the different interests, aims and objectives of the public and the organisation; the tensions between and within interests; and the changes over time.

White (1996) also refined the variables captured from Arnstein's ladder. On power, White showed that even where participation was tokenistic, there was always the potential that it might be "co-opted from below" (White, 1996, p. 12). Thus the citizen should not be seen as powerless, even when that was the intent of the involving organisation. In addition, the power dynamics within an involvement programme were structured by, and related to the direct and indirect ways that power was exercised in society. Bearing on who initiated the involvement, White (1996) showed that the public was always a diverse, rather than a homogeneous group.

Oliver *et al.* (2008) augmented their matrix with an extended framework. The matrix plotted the "researcher's degree of engagement" with the "degree of public engagement" (Oliver *et al.*, 2008, p. 76). This matrix has extended the variable concerning who has initiated the programme with what kind of role they gave to the other party. The framework captured the context of the involvement, although only in terms of location and institution type. While the cognisance of context is welcome, mapping it in such broad strokes limits its usefulness. The authors did find a trend for "collaborative relationships being more productive" (Oliver *et al.*, 2008, p. 79) but they also said of the framework that "none of its features guaranteed public influence of research agendas, but nor did any preclude it" (Oliver *et al.*, 2008, p. 78). There is the possibility, then, that regardless of either party's intent, the context, or the methods used, the involvement that occurs is the result of what happens inside the structure of the programme.

Tritter (2009) developed Oliver *et al.*'s (2008) model, expanding it beyond the boundaries of health research and applying it to health services. One dimension of

this typology, going from individual to collective involvement, is problematic as the individual was always involved as a patient and never as a general citizen. For Tritter, involvement was always collective. Tritter's (2009) second dimension, whether the involvement had direct or only indirect influence over decision-making, has been captured from other typologies. But the third, whether the involvement was reactive (prompted by a specific need) or proactive (permanently in place), is a variable that has been adopted.

Rowe and Frewer (2005) developed a typology based around the direction of information flow. The typology had two levels. At the first level different types of involvement were distinguished by the direction of information flow between an organisation and the public. Thus there were three situations: where information flowed from the organisation to the public; where information flowed from the public to the organisation; and thirdly, where information flowed in both directions between the organisation and the public. The two-way information flow was where "the act of dialogue and negotiation serves to transform opinions in members of both parties" (Rowe and Frewer 2005, p. 255-256).

At the second level of their typology Rowe and Frewer (2005) established a set of variables which, they argued, were associated with maximising the effectiveness of information flow, so that the right information was exchanged, without loss. For example, controlled public selection, facilitation, and face-to-face meetings were all associated with maximising the information flow. The authors may have been right to associate involvement with successful dialogue between the public and the organisation. Whether successful dialogue is synonymous with complete and unimpeded information flow is another matter. The direction of information flow may help to distinguish between involvement projects, and between different phases of the same project. The presence of a two-way flow may highlight the possibility of a dialogue that is transforming opinions on both sides, but it does not appear to guarantee it.

Gibson, Britten and Lynch (2012) drew together constructs from a variety of sources to form a multidimensional typology. One axis of the model was the relative strength of the public, or their power to influence decision-making. This construct

has been captured already. The second axis was “monism to pluralism” (Gibson, Britten and Lynch, 2012, p. 540) or the diversity of involvement mechanisms and activities. In this model, diversity of involvement mechanisms was not only welcomed but seen as essential in order to “engage with people on terms that allow them to participate with other experts on an equal footing” (Gibson, Britten and Lynch, 2012, p. 541).

For Rowe and Frewer (2005), on the other hand, the multiplicity of mechanisms was seen as signalling uncertainty about which mechanisms worked best. There are two reasons for believing that diverse and numerous mechanisms are an asset rather than an issue for involvement. First, the diversity of publics alone makes it unlikely that a single mechanism could be appropriate for every situation, Second, according to Oliver *et al.* (2008), there is no perfect link between involvement mechanisms and successful involvement, making the search for a perfect one of no practical relevance. Therefore, the diversity of mechanisms is captured as a variable in this thesis.

The third axis in the model was “expressive to instrumental” (Gibson, Britten and Lynch, 2012, p. 537) or the extent to which the involvement was dominated by the motivations of the professionals or the motivations of the public. This axis relates to who initiated the involvement, and has been captured already. The fourth and final axis, “conservation to change” (Gibson, Britten and Lynch, 2012, p. 542), plotted the extent to which change was possible and was described as “cross-cutting” (Gibson, Britten and Lynch 2012, p. 542). It is captured here through its relationship with power.

All the typologies are necessarily simplified, ideal types for the purposes of categorisation. Reality can be expected to occupy multiple places along any dimension over time, and possibly at the same time. PPI is unlikely to be static and uncontested. The intent of a programme may not be carried through, or may even be co-opted as it progresses. While some of the commentaries on the typologies acknowledged diversity amongst the public, they all assumed uniformity on the part of the involving organisations. Yet the staff responsible for implementing an involvement programme may not share the organisation’s aims and objectives, and

may not have the skills to bring it about. This diversity within the organisation is explored further in later sections. However, while there might be gaps and caveats, the conceptually significant variables captured from the typologies and their association with effective involvement are shown in Table 2.1 below.

The variables in Table 2.1 are divided into whether they are structural or functional. The structural variables describe the organisational approach to the PPI programme, including the regulations and guidelines governing it. The structural variables should be easily discoverable, give an at-a-glance assessment of the PPI and could be used to compare PPI programmes between organisations. The structural variables capture an organisation's intent with regard to its PPI programme, they are the result of deliberate selection by the organisation. Given the findings of Oliver *et al.* (2008), the structural variables may describe a PPI programme but may not predict its effectiveness. The functional variables, on the other hand, relate to how a PPI programme works in practice. The practice of PPI may not carry out the organisational intent. Individual professionals may extend beyond the intent, subvert it, or pay lip service to it. The functional variables describe how the PPI has come to work. As the detail of how PPI works is not known in advance, the terms used for the functional variables are wider and more abstract. Distinguishing between structural and functional variables thus allows comparison of the organisational intent with the reality.

**Table 2.1 Conceptually significant variables from the PPI literature**

<b>Functional or structural</b>	<b>Conceptually significant variables</b>	<b>Association with effective PPI</b>	<b>Source</b>
Functional	Power	Public have power over decisions. Organisation exhibits willingness to change. Relationships to outside power structures. Public contributors are not powerless.	Arnstein (1969) Pretty (1995) White (1996) Tritter (2009) Gibson, Britten and Lynch (2012)

<b>Functional or structural</b>	<b>Conceptually significant variables</b>	<b>Association with effective PPI</b>	<b>Source</b>
Structural	Who initiates the involvement?	A strong role given by the involving entity to those who are being involved. The involvement serves the motivations of those initiating and those invited.	Arnstein (1969) Pretty (1995) Farrington and Bebbington (1993) Oliver <i>et al.</i> (2008) Gibson, Britten and Lynch (2012)
Structural	Depth of the interaction	Profound interactions are more meaningful than shallow ones.	Farrington and Bebbington (1993)
Structural	Scope of the subject matter	Wide scopes are more meaningful than narrow ones.	Farrington and Bebbington (1993)
Functional	Aims and objectives	The extent to which theses align is related to effectiveness. However, these will compete, contain tensions and change over time.	White (1996)
Structural	Involvement reactive or proactive	Proactive involvement, permanently in place, is identified with more effective involvement than reactive involvement, prompted by a specific need.	Tritter (2009)
Structural	Information flow	Two-way information flow is more likely to signify dialogue and changed understanding than one way.	Rowe and Frewer (2005)
Structural	Face-to-face involvement	Face-to-face involvement minimises the loss of any information flowing.	Rowe and Frewer (2005)
Structural	Facilitation	Facilitation minimises the loss of any information flowing.	Rowe and Frewer (2005)
Structural	Diversity of mechanisms	Diverse mechanisms enable diverse groups to be involved and find a suitable space for dialogue	Gibson, Britten and Lynch (2012)

#### 2.4.2 The enablers of successful PPI

This section analyses the enablers and barriers to successful involvement in an attempt to go below the observable surface of involvement and understand the underlying processes. The aim is to add to the set of structural and functional variables developed in Table 2.1. The lessons from health services and health research on what worked and what did not were remarkably consistent. A series of literature reviews identified the same success factors. This means that there is reason to suppose that admitting the general citizen to the definition of the patients and the public and extending involvement beyond research and services will not diminish the salience of what has been found. The success factors are set out below. Their relative importance is then explored following the findings of Evans *et al.* (2014). Lastly, some ways to determine whether public contributors have been involved effectively are adapted from a mental health service user setting.

Where involvement has been successful, public contributors have been involved right from the beginning of a work programme (Brett *et al.*, 2014 and Evans *et al.*, 2013) when the potential to influence is highest. Involvement worked better if public contributors were involved consistently throughout a programme and over the long term, rather than periodically after long intervals (Brett *et al.*, 2014 and Staley, 2009). Involvement needed to be well planned, and the planning must have encompassed clear role definition, time, budget, training and support for involvement (Brett *et al.*, 2014, Staley, 2009, Evans *et al.*, 2013).

Other success factors included a positive attitude towards involvement, trust and respect between the individuals (Brett *et al.*, 2014), sufficient public contributors to support each other, and preferably a critical mass (Evans *et al.*, 2013). Involvement should ideally be managed by a consistent set of people (to aid relationship building), public contributors should feel comfortable raising their issues onto the agenda, and they should receive feedback on how their input has helped (Evans *et al.*, 2013). Finally, Staley (2009) suggested that involvement should be linked into formal programme management, so that there is a clear pathway into an organisation's decision-making structure. These success factors can be added to the groups of either structural or functional variables shown in Table 2.1.



In their realist evaluation of eight involvement case studies, Evans *et al.* (2014) asked whether all of these factors must be present for involvement to be successful, and if not, which ones were the most important. They found that while a culture and institutional history of support for involvement helped to shape the way involvement was done, the most important success factor was leadership from the programme manager. If the organisation had a strong culture of involvement, and the programme manager was open to involvement, then this was also enough. Commitment from the programme manager, or at least openness, led to a senior team member being given responsibility for involvement, which meant that resources were allocated to it. Evans *et al.*, (2014) found resource allocation to be more about allowing sufficient time to provide briefings, training, support and feedback than it was about formal budgeting for expenses or payment for time. Once sufficient time was allowed for involvement, then relationships between public contributors and other team members could develop and grow. In turn, this meant that public contributors felt they could make contributions. If the public contributors received positive feedback on their contribution then this both fed and was fed by a positive impact on the confidence and motivation to contribute more.

Evans *et al.* (2014) were trying to understand what factors led to a positive impact on the quality of research and on the public contributors themselves, but their understanding of the relative importance of different success factors may apply more generally to other types of PPI. They found that some “field[s] of research” (Evans *et al.*, 2014, p. 49) or types of work lent themselves better to successful involvement because the public could be invited from the beginning, have a role throughout the work, and could be involved over the long term with a consistent set of team members. Within a suitable work area, they then found that personal commitment and interpersonal skills were more important than institutional processes and structure. This finding might explain why Oliver *et al.* (2008) found that no particular variable from their framework either guaranteed or precluded successful involvement. If the key to successful involvement lies in personal commitment and interpersonal skills, then comparing involvement programmes on the basis of their structural characteristics will not explain success. This finding seems to suggest that the functional variables will have a greater affect on the effectiveness of PPI than the structural variables.

That the findings from health research (by Evans *et al.*, 2014 and Oliver *et al.*, 2008) might apply more widely is reinforced by a similar set from health policy decision making. Li *et al.* (2015) asked involvement professionals, “How would you know if public involvement was used in policy decision-making?” (Li *et al.*, 2015, p. 19). Professionals indicated that their aim was to permit input from the public, but that this input was one among many.

Li *et al.* (2015) reported that three soft skills, rather than structural characteristics, were seen as necessary precursors to public input to policy decision making. The first was listening, which must be genuine, and reflect the commitment of the individual to PPI (so that listening is genuine rather than for form’s sake). If the culture of the organisation was supportive then this seemed to permit institutional openness about what input was being sought and for what purpose. Health sector professionals were more willing to listen if the public contributor was seen as credible, and this credibility depended on them being representative (Li *et al.*, 2015). The issue of how an involved general citizen might be credible, even though they cannot be representative, is addressed later under the heading of legitimacy.

The second soft skill was mediation by the involvement professionals to promote the conversation. The need for an intermediary is disputed. For example, Crepaz-Keay’s (2014) indicators for effective involvement would have it led by a public contributor in a paid role rather than having an involvement professional as an intermediary. Perhaps, though, the soft skill of facilitation is required, rather than an involvement professional as a facilitator. The final soft skill reported by Li *et al.* (2015) was that of providing feedback to the public, not just acknowledging input, but detailing whether or not it had not been used and why.

Table 2.2 below summarises the enablers for successful PPI. It shows that each enabler can be thought of as an additional structural or functional variable, or adds new associations with effectiveness.

**Table 2.2 The enablers for successful PPI**

<b>Group</b>	<b>Conceptually significant variables</b>	<b>Association with effective PPI</b>	<b>Sources</b>
Structural	Involvement from the beginning.	More scope to influence the agenda at the beginning.	Brett <i>et al.</i> (2014); Evans <i>et al.</i> (2013)
Structural	Involvement all the way through.	Regular, rather than sporadic involvement.	Staley (2009)
Structural	Clear role definition	Public contributors and staff understand the public's contribution.	Evans <i>et al.</i> (2013)
Structural	Budget	Funds are available to support involvement.	Brett <i>et al.</i> (2014)
Structural	Training for public contributors	To allow the public to develop expertise, if they wish to.	Brett <i>et al.</i> (2014); Staley (2009); Evans <i>et al.</i> (2013)
Functional	Leadership	A positive attitude or at least an openness to PPI. Feedback to the public contributors. Allowing time for PPI. Listening.	Brett <i>et al.</i> (2014); Evans <i>et al.</i> (2014); Evans <i>et al.</i> (2013); Li <i>et al.</i> (2015)
Functional	Trust	Trust and respect between the individuals.	Brett <i>et al.</i> (2014)
Structural	Critical mass of public	Public contributors are not involved alone.	Evans <i>et al.</i> (2013)
Structural	Consistent set of managers	Aids relationship building	Evans <i>et al.</i> (2013)
Functional	Power	Contributors can put items on the agenda. Link to the management structure.	Evans <i>et al.</i> (2013); Staley (2009)
Functional	Leadership	A positive attitude or at least openness to PPI. Feedback to the contributors. Allowing time for PPI.	Brett <i>et al.</i> (2014); Evans <i>et al.</i> (2014); Evans <i>et al.</i> (2013)

<b>Group</b>	<b>Conceptually significant variables</b>	<b>Association with effective PPI</b>	<b>Sources</b>
Functional	Credibility	Experience-based.	Li <i>et al.</i> (2015)
Structural	Facilitation	To promote dialogue.	Li <i>et al.</i> (2015)

Crepaz-Keay (2014) used Delphi rounds to construct a list of indicators for effective involvement in mental health services. Those indicators relating to the individual do not serve the purpose here as they concerned aspects of personal care. But those relating to the operational and strategic levels seem to offer insight into what signifies effective involvement. Adapting Crepaz-Keay's (2014) table of final indicators by choosing only those indicators from the operational and strategic levels and changing the terminology to that used in the rest of this thesis, the indicators are laid out in Table 2.3 below.

**Table 2.3 Involvement indicators**

Operational	<p>Public contributors involved are supported to meet together regularly.</p> <p>Training is offered for public contributors who get involved.</p> <p>Public contributors are offered payment for their time.</p> <p>Public involvement is led by a public contributor in a paid role.</p> <p>Public contributors contribute to the production of official information.</p>
Strategic	<p>New initiatives are jointly designed or co-produced by public contributors and professionals</p> <p>Several public contributors sit on the governing body</p>

The data in Table 2.3 was extracted and adapted from Crepaz-Keay (2014, table 6.6, p. 117, titled 'The Final Indicators'). Permission to use this table has been granted by the author.

The Crepaz-Keay (2014) indicators described a model of involvement where trained, paid contributors work jointly with professional staff and are woven into the fabric of organisational decision making. However, when these indicators are added in to the set of conceptually significant variables, they become part of the structural variables. Other research (Evans *et al.*, 2014) showed that the interpersonal skills of an organisation's leaders were more important than the structure of PPI in predicting success. A trained, paid public contributor could struggle to be effective if the governing body was not, for example, led by someone who is open to PPI.

The review of the enablers and barriers to successful involvement finds that they are remarkably similar regardless of context, and likely to apply where the involvement is of a general citizen. The enablers provide additional concepts to add to the structural and functional variables. Importantly, research suggests that the functional variables will provide stronger explanations of successful involvement than the structural variables. Organisations can set up strong mechanisms to involve the public, but it is the way these mechanisms work, or are made to work, that determines if the public are really involved.

### **2.4.3 Value of PPI**

This thesis seeks to evidence the value of PPI. Typically, studies in health have sought the impact of PPI rather than the value. This section therefore begins by looking at both the evidence and the methodologies for understanding the impact of PPI, before attempting to reconcile the ideas of impact and value.

Conklin, Morris and Nolte (2012), in their review of the impact of involvement on health policy, found scant evidence of its effects. They reported that impact has mostly been measured by interviewing the public and professionals about their perceptions. Some studies attempted to measure change without a definition, a long enough time frame, or a point of comparison. There was almost no measurable data. Instead, there were policies to involve the public, and much reported activity. Especially where involvement was held to be a right (for example, in mental health service user involvement) then it might have been sufficient for the activity to result in an effective process of PPI, rather than a change in outcomes. Certainly Turner

(2010) found a block between the activity of involvement and any real change that could be attributed to it. Other studies, though, have reported a range of impacts.

The practice of understanding the impact of involvement through interviews, while it has limitations, does seem to be a reasonable method of discovery when that impact is the perceived effect on the individuals themselves. There were multiple reports of impact on both the public contributors and the professionals. The most comprehensive list was from Staley (2009). For public contributors the positive changes were in the acquisition of new skills: specific ones (such as research techniques), general ones (such as computer skills or team working) and new knowledge (through exposure to new information). Public contributors also reported an impact on their self-confidence, peer support and friendship groups as well as receiving enjoyment, satisfaction and financial reward from involvement. There were negative changes as well, such as becoming over-burdened either with the workload or with an emotional toll, becoming frustrated, or being targeted in the media. For the professionals the positive changes were reported as a better knowledge of the community, a rewarding and enjoyable work experience, career benefits, and a change in attitude towards the value of public contribution. The negative changes reported were the need to share power, for more resources, more time and additional skills in order to involve the public. In a later work Staley (2015) argued that professional skills and approach were both the biggest determinant of success in PPI, and the area where the greatest impact is felt.

From research, in particular, there was evidence that involvement has an effect on the process, that is, the way the work gets done. Brett *et al.* (2014) and Staley (2009) reported that public contributors could have an impact at every stage of the research process from the research question through to the dissemination of the results. Interviews with research professionals have revealed that public contributors seem to be able to help researchers make their research more relevant, more responsive to public priorities, and to give advice on different ways of recruiting research subjects. The effects were not always reported to be positive. The changes wanted by the public sometimes undermined what researchers regarded as good science, occasionally meaning that results were inconclusive because of doubts around the methods adopted (Staley, 2009). Evans *et al.* (2013) also found evidence of impact

on the process in cancer commissioning. Public contributors held professionals to account for promised improvements, and influenced the way a public consultation was done.

PPI can also affect what work is done. In research there is evidence, for example, that what was measured could be changed by public involvement. Staley (2009) reported that rather than measure standard cognitive skills, public contributors had driven measurement of important life skills like memorising a shopping list. In services Mockford *et al.* (2012) found that while the public were involved in service planning and development, there was little description of the effect the public had. Effects appear to have been easier to trace in the production and dissemination of information. Either public contributors had more success in influencing relatively simple pieces of work such as leaflet design, or public contributor effects were easier to trace if the piece of work was simple. When a team works together on designing and delivering a complex project, the particular impact of one or two individuals may be difficult to recall or demonstrate.

Public contributor influence on outcomes was the hardest of all to provide. As Mockford *et al.* (2012) wrote, “Some forms of impact were relatively easy to demonstrate such as the impact on leaflet design; however the effect on others of receiving the literature was unknown” (Mockford *et al.*, 2012, p. 37). Evans *et al.* (2013) said, “intermediate or organisational outcomes are easier to demonstrate than health outcomes” (Evans *et al.*, 2013, p. 8). In research, Brett *et al.* (2014) described how public involvement created advocates for disseminating and implementing the results. This could be a mechanism for the way involvement has an impact on health outcomes, but evidence of a direct link between public involvement and changing health outcomes was not provided in the literature. Not only would this kind of evidence require long-term studies with clear measures, but the specific impact of involvement rather than other factors would have to be traced.

Staley (2009) pointed to evidence of impact on the wider community, even though it fell short of being evidence on health outcomes. There was evidence that public involvement built trust in and therefore acceptance of research, especially in communities which had been badly treated in the past. This led to better

relationships between professionals and the community, and was also reported to have led to improved services and increased service use. Where public involvement was through community organisations, they were reported to have benefitted in terms of improved credibility, learning, public recognition, improved ability to represent the interests of their community, to link their community to services and to build new relationships. Staley (2009) suggested that there was evidence of new services being provided for previously unmet health needs and of improvements to existing services. Finally in this category, the learning and development that public contributors experienced could be such that their ability to bring about change through advocacy was enhanced.

Staley's (2009) examples of these wider community impacts tended to be from groups that were previously marginalised and hard to reach. While the study covered only research, perhaps the key learning is that the biggest impact from public involvement is likely to be among groups whose interests are not well represented in any other ways, those groups that, in practice, are hardest to involve. In terms of evidencing the value of PPI, it is important to capture who is involved as a structural variable. The PPI may be more valuable over the long term if the public contributors are diverse in terms of "gender, ethnicity, belief, cultural class, sexuality, age, [and] impairment ..." (Beresford, 2013, p. 142).

Staley (2015) highlighted a debate between those who describe the evidence of involvement's impact as anecdotal and therefore of limited value, and those who argue that involvement is a right, so that evidence to justify doing it is not essential. Conklin, Morris and Nolte (2012), whose review found strong evidence to support only the benefit to individuals, asked whether the focus on impact is the right one. If there is a developmental impact on individuals, and public involvement in health is the right thing to do, then perhaps that is sufficient. However, if budgets for public involvement are to be maintained in the difficult financial circumstances of the English NHS described by Iacobucci (2016), then the pressure to demonstrate that it has an impact that goes beyond the people who were in the room is likely to continue.



Staley argued that it is worthwhile understanding how to do involvement well and what impact it has, but the evidence will not come in the form of randomised control trials (RCTs) because involvement is not a standardised medical intervention.

Wilson *et al.* (2015a) also found RCTs wanting, not because involvement is not an intervention, but because it is a complex one, resting on combinations of dynamic social processes. The Public Involvement Impact Assessment Framework (PiiAF) explicitly recognises PPI as a complex social process, and in response presents a two part, iterative process to help research teams develop impact assessment plans (Popay and Collins, 2014). The framework does not set out a simple checklist, but rather describes a journey that a research team and their public contributors can travel, from capturing the values associated with PPI to the likely impacts. The developers of PiiAF argue that the impact of PPI should be assessed for the following reasons: to be in line with good practice in assessing interventions, to justify the resources, to persuade doubters, to attract funding, to avoid harm, and to provide public contributors with feedback (Popay and Collins, 2014).

PiiAF may also answer a further issue raised in this debate. Staley (2015) argued that no new categories of impact had arisen since 2009. Hence a new focus was required, on understanding how outcomes were achieved in different contexts. Wilson *et al.* (2015a) proposed realist evaluation as a way to build cognisance of context into PPI assessment. PiiAF also builds context in: phase three of developing an impact assessment plan asks the research team to identify the effects of context (Popay and Collins, 2014). However, in terms of its relevance to this thesis, PiiAF presents some challenges. First, the aspects of context highlighted (Popay and Collins, 2014, pp. 48-50) do not include any prompts to consider the form of the organisation or the implications of that organisational form on PPI. The PiiAF framework may thus not be a specific enough tool for the research questions being posed in this thesis. Second, PiiAF has been developed for “researchers who wish to design an assessment of the impact of public involvement in their research” (Popay and Collins, 2014, p. 7). PiiAF is thus intended for project teams (including public contributors) themselves to use to assess their PPI. It is not clear, then, that PiiAF would be an appropriate framework for an external researcher to employ. Third, and related to the previous point, PiiAF’s nature as a journey rather than a checklist establishes it as an approach that requires time and commitment from an entire

project team. The nature of this commitment would appear to be more extensive than the acquiescence to interviews and observations, for example, and there is a risk that this commitment may be out of reach for a doctoral researcher. Finally, the framework was published in 2014, and so there has been little time for peer-reviewed publications to use and reflect on PiiAF. The sole study that appeared in a search for journal articles was co-authored by two of the developers (Popay and Collins). Collins *et al.* (2018) use a reflective case study to draw lessons from using PiiAF in drawing up a plan to assess the impact of PPI in a research project. However, their paper closes with the formulation of the plan, so there is no opportunity to examine a completed impact assessment drawn up using the framework.

In their paper reflecting on the use of PiiAF to generate an impact assessment plan, Collins *et al.* state the reasons for using the framework as including “to test PiiAF; to make the approach to [PPI] ... more explicit; to generate ideas about how to develop the [PPI] strategy ... ; and to create an evidence base to support [PPI] costs in funding applications” (Collins *et al.*, 2018, p. 6). These aims illustrate that the search for impact from PPI may, in practice, be a relatively narrow exercise, despite PiiAF’s explicit suggestion that researchers be sensitive to the positive and negative, intended and unintended impacts (PiiAF, 2014). In order to further explore the idea that the impact literature on PPI may ask questions that are too narrow, this section uses ideas developed by Alvesson and Sandberg (2011) who proposed six steps for “identifying and challenging the assumptions” (Alvesson and Sandberg, 2011, p. 247) inherent in existing research questions, in order to ask new questions. Here, steps one to three are used in order to examine the questions relating to impact more closely. The domain of literature covering the impact of PPI has been identified in this section of the thesis. A key assumption contained within this domain is the idea that evidence-based knowledge will provide a compelling argument to convince the whole range of audiences in PPI: funders, professionals, and the public themselves. By extension, this assumption also means that while “there is broad agreement that the public have a right to be involved in research related to health conditions or issues related to them” (Collins *et al.*, 2018, p. 2) that this right by itself is insufficient to convince that same set of audiences, meaning that there really is no broad acceptance of a fundamental right to be involved. A fundamental right does

not require justification by its impact. Staley (2015) bridged these positions by suggesting that even if evidence of impact was not essential (because involvement is a right) it is helpful and provides insight into how involvement can be improved. However, this position still holds the researchers responsible for improving involvement.

The analysis above serves to direct the search for evidence of the value of PPI. Value is held to be a wider term than impact and as such is deliberately used in this thesis. Value captures any effects of PPI, that is, any changes attributable to public contributors and the contributions they make. The fundamental consideration, then, is what the public contributors actually do and say when they are involved, rather than the needs or expectations of any audiences to the involvement, and rather than an evaluation that constrains the assessment to measurable impacts that have been anticipated by the research team. Value encompasses both intended and unintended effects. The effects may be on process (the way of running a project), outputs (understood as the direct artefacts produced by a project), on outcomes (the results, intermediate or final, of having run the project), or impact (the extent to which the outputs and the outcomes have had positive effects). This open approach to value is held as the most likely to encompass the general citizen involved in work where they have no experiential expertise. Asking a question about value does accept that although involvement is a right, professionals and the public share an interest in improving it. This thesis holds that asking a question about value rather than impact is more likely to result in findings that will empower public contributors themselves, and serve their interests rather than just the interests of the professionals or the institution.

#### **2.4.4 Typologies in the IONs literature**

This section moves to the right-hand side of Figure 2.3, to look at typologies in the ION literature. The purpose is to seek out explanatory variables for describing the ways that IONs operate. The focus is on IONs in the public sector and characteristics that apply to networks in a healthcare setting.

The typologies relevant to this section are those that extend the adopted organisational definition of a public sector ION as the organisation implementing PPI plus its autonomous, formal members, where the organisation has been set objectives by government that can only be achieved by collaborating with its members. Furthermore, the IONs considered here were: formed to meet a range of goals, rather than a single purpose such as sharing knowledge; and at least semi-stable rather than intending to disband once the goals were met (Hoberecht, Joseph and Southern, 2011). Keast *et al.* (2004) distinguished between networking (making informal connections), networks (with formal connections) and network structures (where members move beyond co-ordination and become inter-dependent).

Other authors have also sought to characterise networks on the basis of formality.

For Ferlie *et al.* (2009, p. 144), it was one of six axes: -

1. The complexity of the context;
2. Whether the network was mandated, emergent (or organic) or a combination;
3. The extent to which it was resourced;
4. The extent of formality;
5. The number and heterogeneity of stakeholders;
6. The extent to which shared values drove the way work got done.

Ferlie *et al.*'s (2009) comparative study ranged eight networks in relative placement along these axes. However, for a single case study, it is possible to make only tentative statements about where the ION falls for all except the second axes listed. The axis of mandated, organic, or combination is explored in detail by additional authors in the ION literature.

Where an ION has been mandated by government, rather than emerging as a response to a particular problem, Popp and Casebeer (2015) raised two fundamental questions. The first was whether the ION represented a serious attempt at addressing wicked problems, or merely an attempt to be seen to be doing something. The second was whether or not collaboration in an ION could be mandated at all. Membership of the ION can be mandated, but collaboration relies on good working relationships that cannot be brought into being by government diktat.

Although this debate is at the inter-organisational level, it has echoes for PPI. Public involvement is part of a government commitment in the English NHS and extends to “widespread adoption of shared decision-making” (Department of Health, 2012, p. 1). Citizens can be placed in a room with professionals, but collaboration will not necessarily be the result. Whether effective involvement occurs and what its value might be are questions the PPI literature is still asking. Even within emergent IONs, where the organisations themselves decide to form a network, collaboration is a difficult task (Popp and Casebeer, 2015).

In order to categorise IONs further, Provan and Kenis’ (2008) typology was considered. Where an organisation is set up for the centralised co-ordination of its members, it can be called a “network administrative organisation”, or NAO (Provan and Kenis, 2008, p. 236). The term NAO describes the immediate organisational context for PPI in this thesis and the wider network is the NAO’s formal member organisations. For an ION, having either an NAO or a “lead organisation-governed network” rather than a “shared participant-governed network” (Provan and Kenis, 2008, p. 235) is predicted to increase effectiveness where network members do not trust each other, where the number of members is high, where the network goals are not strongly shared, and where achievement of the goals requires a collaborative skill set. Thus the term NAO is used in this thesis as it fits the context well, delivers predictions about effectiveness, and is widely used in the ION literature.

However, there is some reason to question whether or not all ION structures deliver on the value associated with collaborating. Some authors described networks with NAOs as an organisational form close to single organisation hierarchies (Popp *et al.*, 2014) perhaps because they have access to management practices for projecting authority such as holding members to commitments, working through obstacles, performance measurement, and attracting government money (Kelman, Hong and Turbitt, 2013). These management practices for projecting authority, together with already successful member organisations were associated with ION effectiveness even though their association with collaboration may be dubious (Kelman, Hong and Turbitt, 2013).

Another way of categorising IONs is using a lifecycle approach. The attraction of this approach is the link many authors (Ferlie *et al.*, 2009; Turrini *et al.*, 2010) made between longevity and effectiveness. This link appears to be related to the time it takes for relationships to build and for understanding between actors to grow (Popp *et al.*, 2014). Many authors associated the way a network is formed, and the way decisions are made, with later success (see Bryson, Crosby and Stone, 2006). There is a balance to be found between getting the tasks done and setting the tone for inclusive collaboration right from the start (Popp *et al.*, 2014). The difficulty with a lifecycle model is that it can be hard to distinguish between the phases, and even harder to place a going concern into them. The principal lesson seems to be the importance of the initial stages to the subsequent collaboration.

Rather than yielding new structural or functional variables, the ION typologies help to further identify and describe the context in which the PPI programme operates. Moreover, the ION typologies serve to emphasise the importance of the functional variables. In particular, understanding how a mandated collaboration works in practice is vital.

#### **2.4.5 The enablers for collaboration in IONs**

With the immediate context for PPI categorised as an NAO, the enablers and barriers of success for IONs may help to understand some of the underlying processes. This section begins with a focus on the particular barriers and enablers for mandated NAOs, considers the tensions inherent in any collaboration and concludes that managing and negotiating these tensions is inescapable, regardless of how the network is structured and organised.

Popp and Casebeer (2015) reviewed the enablers to success in an article that focused solely on mandated networks. For these authors, mandated networks were the most difficult form of network and so more attention needed to be paid to building “collaborative capacity” (Popp and Casebeer, 2015, p. 231). The authors reviewed the building blocks of collaborative capacity, asking what particular issues mandated networks might have. For example, they might not get the buy-in they needed from members, and might need more time than emergent networks to bring

everyone together. Unless the network mandate was built on top of existing, good relationships, genuine trust might not exist between members from the outset. A mandated network might need more time for trust to develop. The members' goals might not be aligned. Sometimes the only alignment was shared dislike for the mandate. Achieving alignment in these circumstances might take both more time and resources. Although the mandate could bring extra resources, transaction costs could be higher if trust was low. The network formation might change the system risk. For example, the mandate might eliminate redundancy, in which case the failure of the network would lead to a bigger risk.

The mandate also had an effect on legitimacy. It could improve the network's legitimacy in the eyes of those outside the network, and yet diminish it for those inside. In addition to collaborative capacity, Popp and Casebeer (2015) describe the way networks are managed as important, "the performance of a network is often tied to the availability, type, and quality of leadership and management" (Popp and Casebeer, 2015, p. 233). If the member organisations were not sufficiently bought-in, then the leadership might have to be more centralised than was desirable. The crux of this assessment seems to be that mandated networks may require more time (and possibly resources) to build collaborative capacity. The elements of collaborative capacity are similar to the functional variables noted from the review of PPI.

While Popp and Casebeer (2015) saw non-alignment of goals as a particular issue for mandated networks, Popp *et al.* (2014) saw an NAO as a good way to focus a network on overarching goals and to go beyond the individual disagreements of members. The tension between individual members' goals, and the lack of alignment between members might be exacerbated in a mandated network, and eased by an NAO, but it was one of a recognised set of tensions that network managers must negotiate. As in the previous section, the more diverse the membership, the worse these tensions were likely to be. Popp *et al.* (2014) summarised these tensions as being between efficiency and inclusiveness; internal and external legitimacy; flexibility and stability; and between having goals that were close enough to work together, but far enough apart to make collaboration worthwhile.

Huxham and Vangen (2005) went further, making the exploration of tensions in collaboration the heart of their book. For them the tensions are never resolved. Instead they are negotiated all the way through. It's not that work on aligning goals happens at the start, and then a collaboration runs smoothly thereafter. It is that the work to manage the different goals continues throughout and is never finished. In their research with practitioners, Huxham and Vangen (2005) found that interviewees yearned to have the tensions resolved. For example, interviewees said that collaborations would work better if all the organisations could agree on clear goals right from the start. The participants saw these tensions as barriers to collaboration, and their removal as enabling collaboration. Thus the authors found that asking people about their experiences in collaborations did not reveal what was going on beneath the surface. The work of collaborating entails constant management and negotiation of the tensions involved in having a diverse set of organisations trying to achieve something together. Huxham and Vangen's (2005) experience provides a useful reflection on the extent to which interviews of public contributors and researchers in PPI might also suffer from the same issue. In the section that describes the enablers and barriers to involvement, participants saw the resolution of collaborative tensions as enabling involvement.

Mandated networks may suffer more from the barriers to collaborative working, as the mandate may exacerbate the tensions which all networks experience. An NAO may be an effective way to manage through these tensions, but the literature demonstrated that the NAO should not be expected to provide a resolution to the tensions, but rather a focus for the constant management and negotiation of them. While the ION literature did not admit individual public contributors into the network, there appear to be common themes across different forms of collaboration.

#### **2.4.6 Value of IONs**

This sub-section explores value in the ION literature, as shown in the bottom, right-hand side box of Figure 2.3. While this thesis asks questions to evidence the value of PPI in an ION, rather than the value of the ION *per se*, the ION literature provided several helpful approaches. As this thesis deals with mandated IONS in the



public sector, value is not explored from the perspective of economy (cost per output) or efficiency (the ratio of inputs to outputs). The concept of value used is not a quantitative measure. Rather, value is an indicator (a qualitative statement) related to effectiveness or the ability to meet requirements (Boland and Fowler, 2000).

Moore (1995) argued that the requirements for value in the public sector, or “public value” (Moore, 1995, p. 28), are twofold. First, there is the requirement to satisfy the direct beneficiaries of public services, the clients. Second, there is the requirement to satisfy a collective citizenry in their ideas and aspirations for the common good. The fulfilment of the twofold requirements is then evaluated not by cost efficiency, but by fairness, or the extent to which a public service is “deployed generally and for the good of all.” (Moore, 1995, p. 47). The notion of public value suggests that value in a health-sector ION should be sought at both the client and citizen levels. While acknowledging the failings of democratic politics in delivering a collective view of the common good, Moore suggested that broad political agreements delivered through elections are the way that citizens evaluate the “story” (Moore, 1995, p. 39) of public services put to them by the professionals. Moore’s views of public value seem to open a role for public contributors to interject in health research and service provision on behalf of both clients and the broader citizenry, and to see PPI as part of both the story-making and the evaluation of health sector organisations.

For Bryson, Crosby and Stone (2006) the purpose of collaboration is the creation of public value, which could not be created by any one of the organisations alone. This clearly complicates the assessment of IONs. Not only is the search for effectiveness in meeting requirements, but also for value that would not have been delivered if the network had not been formed (Popp *et al.*, 2014). Value for IONs is thus similar to the value of PPI, in that it is related to the effects or changes traceable to the network and which would not otherwise have occurred. Popp *et al.* (2014) made several suggestions: that evaluation should be designed as the network is formed; that it should not be done in the “early years” (Popp *et al.*, 2014, p. 76); and that the expectations should be set according to the life cycle stage of the network. In a similar vein, Keast *et al.* (2004) suggested that assessing networks using standard outcome measures risked overlooking the unique benefits they bring: of “systemic

change, relationship building, innovative operating procedures and community inclusion” (Keast *et al.*, 2004, p. 370). These authors, then, saw the key outcome of networks as the synthesised network processes that emerge, rather than the outcomes this synthesis achieves. Popp *et al.* (2014) said, “processes and outcomes are both important” (Popp *et al.*, 2014, p. 78) although by outcome, the authors here seemed to mean outcome in terms of network structure.

Provan and Milward (2001) stated that “it is reasonable and desirable to evaluate networks based on their effectiveness” (Provan and Milward, 2001, p. 422) but added that this is harder than evaluating the effectiveness of single organisations because of the diversity of stakeholders. Not only this, but “networks must contend with the joint-production problem of multiple agencies producing one or more pieces of a single service” (Provan and Milward, 2001, p. 422). The joint production problem is the difficulty of demonstrating afterwards whether changes were down to the network, or to individual members, and which individual members contributed. This problem has echoes for PPI where it is hard to tease out the impact of public contributors where they contribute as part of a team solving complex problems.

Despite the difficulties, the ION literature has developed some conceptual models for thinking about value (or effectiveness in the terms of the ION literature). These models offer the possibility of adaptation for the purposes of evidencing the value of PPI in an ION. The concept development begins with a model taken from Provan and Millward (1995), an adapted version of which is shown in Figure 2.4. The precise ION structure, context and effectiveness variables have been removed in order to leave the fundamental relationship, where network structure, acted upon by context, leads to effectiveness.

**Figure 2.4 Network effectiveness**

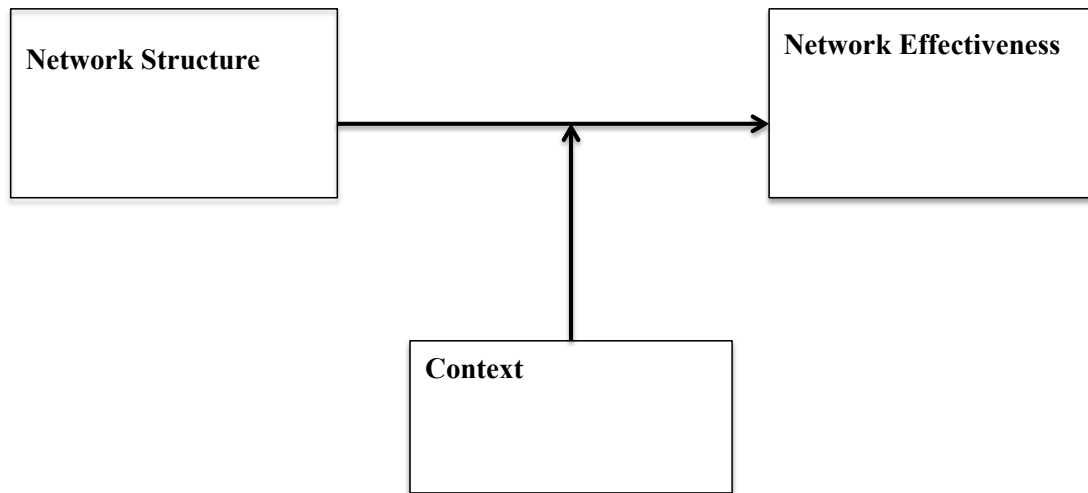


Figure 2.4 shows an adaptation of Provan and Milward (1995, figure 1, p. 24 titled ‘A preliminary model of network effectiveness’). It is reproduced with permission from SAGE Publications.

Provan and Milward (2001) went on to break down network effectiveness into three levels: the community, the network, and the network members. The community level’s primary focus was the clients who should benefit from more effective provision. But it also included voluntary groups representing the clients, the NAO as the agent of the clients, funders, politicians and the general public “which pays for many of the services needed by clients through taxes and which reaps the indirect rewards of a healthier, safer community” (Provan and Milward, 2001, p. 417). These ideas echo the twofold requirements of Moore’s (1995) clients and citizens. Figure 2.5 shows Provan and Milward’s (2001) ideas on evaluating effectiveness at multiple levels, added into the stripped down version of their diagram.

**Figure 2.5 Network effectiveness with multiple levels**

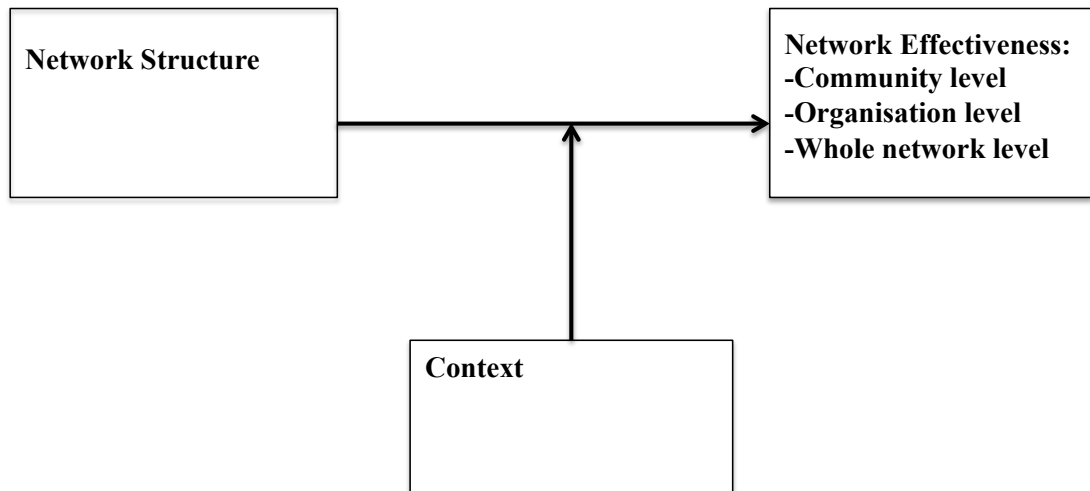


Figure 2.5 shows Provan and Milward's (1995) network effectiveness model with ideas of effectiveness at multiple levels added from Provan and Milward, 2001, © 2001 the American Society for Public Administration.

A further development of this model of network effectiveness, or value in this thesis, comes from a literature review. Turrini *et al.* (2010) showed that “network functioning” (Turrini *et al.*, 2010, p. 545) should be added to network structure as a determinant of effectiveness. In particular, the literature review highlighted the role of the behaviour of network managers. Turrini *et al.* (2010) added significant detail to Provan and Milward’s (1995) original model. However, for the purposes of this thesis, the most important addition was network functioning, as shown below in Figure 2.6. In addition, community level effects could foster a more benign context for an ION to operate in (Turrini *et al.*, 2010). Communities with a history of collaboration, where collaboration is valued and which participate in public activities can contribute to a context in which IONs succeed. This feedback loop has also been added to Figure 2.6.

**Figure 2.6 Network effectiveness with functioning and feedback**

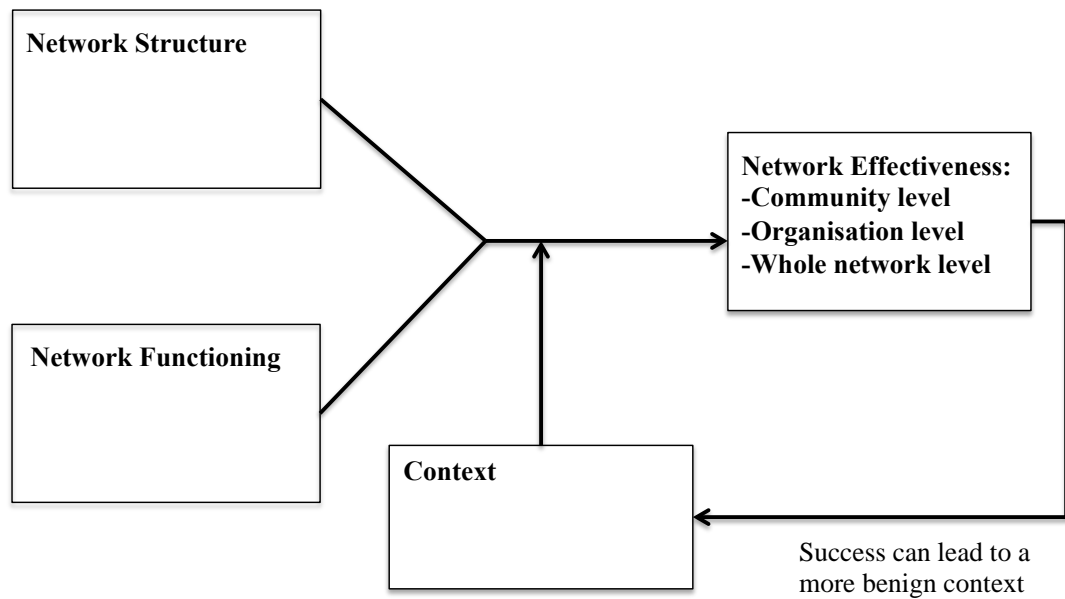


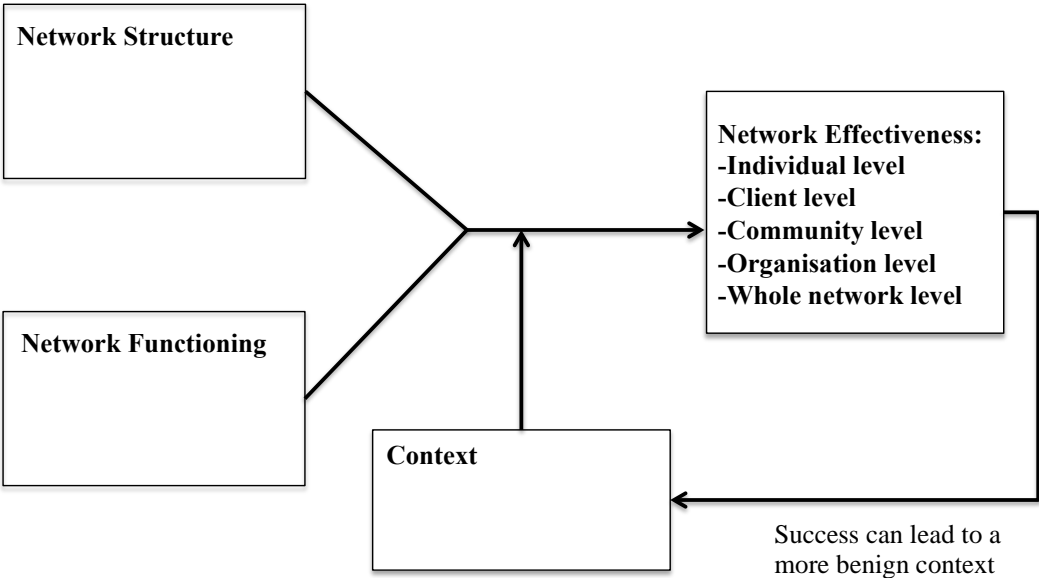
Figure 2.6 shows ideas of network functioning and feedback added to the model of network effectiveness from Turrini *et al.*, 2010, © 2009 Blackwell Publishing Ltd.

Ferlie *et al.* (2009) used and developed Turrini *et al.*'s (2010) model in a study of eight networks. Ferlie *et al.* intended to study PPI in these IONs, but they did not find much evidence of it. However, two concepts useful to this thesis emerged. First, instead of assessing ION effectiveness using direct client measures, Ferlie *et al.* (2009) develop a proxy. If the ION was implementing evidence-based practices, and these practices were implemented successfully, then Ferlie *et al.* (2009) took the positive impact on health outcomes as read. Second, Ferlie *et al.* (2009) intended to study PPI at the levels of both community effectiveness and at a new level of stakeholder effectiveness. Ferlie *et al.* (2009) defined their public as users, and thus stakeholders. However, for this thesis the public are not stakeholders in this sense. Hence, prompted by Ferlie *et al.* (2009), this thesis adapts the model further by breaking out the client level of effectiveness as a separate and additional level, as shown in Figure 2.7.

One final development to this overall model of network effectiveness seems to serve the purpose of evidencing the value of PPI in an ION. Hill, (2002, cited by Popp *et al.*, 2014) reportedly expanded the number of levels at which network effectiveness

was considered by adding the individual level. The description of this level is “assessment of the impact that the network has on the individuals who interact in the network on behalf of their respective organisations and on individual clients” (Popp *et al*, 2014, p. 79). The types of outcome listed (such as improved job satisfaction and client satisfaction with services) were not written with PPI in mind. However, in PPI the evidence showed that there is an effect on both individual professionals and on the public contributors themselves. Thus breaking out the individual level gives this thesis a way to look for the value of ION-based collaborations at a range of levels, including the individual, and the client as well as the community, the organisation and the network, see Figure 2.7.

**Figure 2.7 Network effectiveness with added levels**



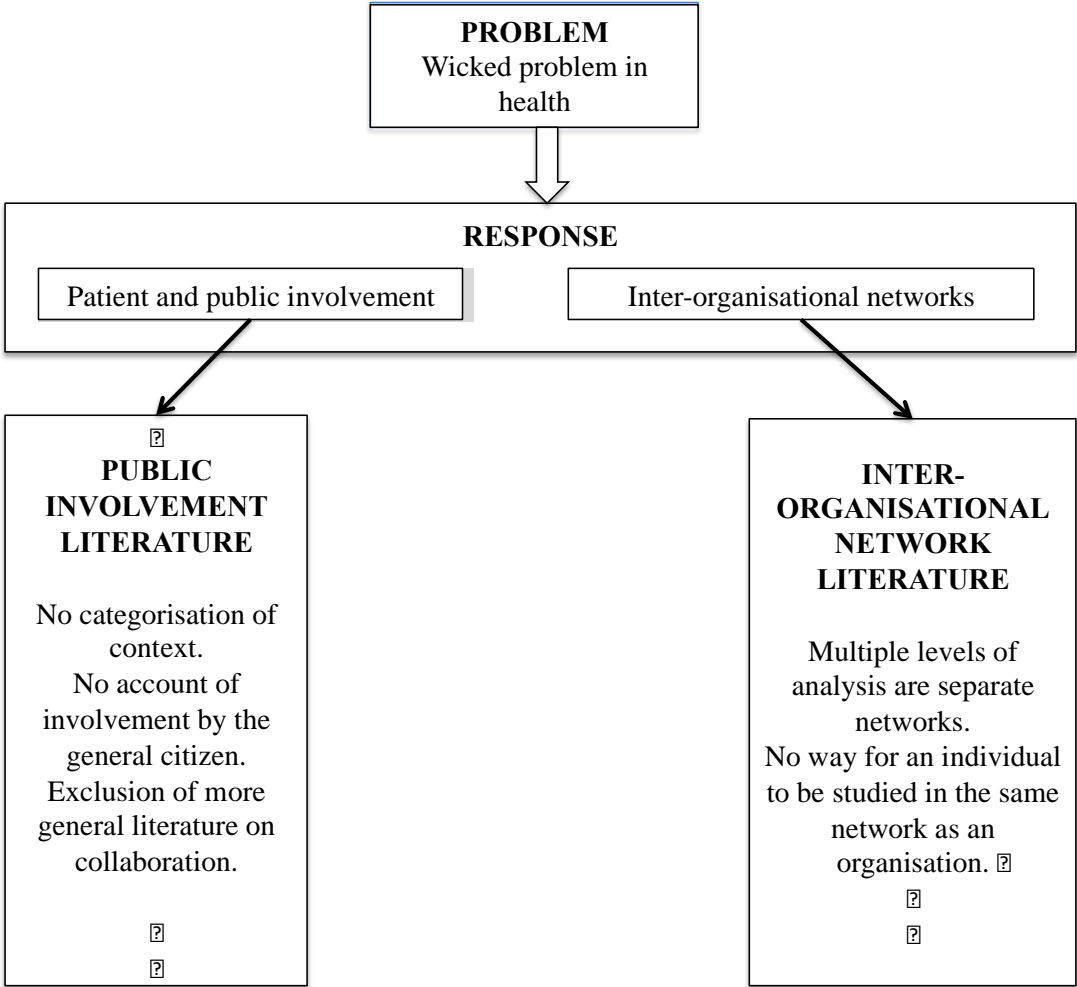
The analysis of value, culminating in Figure 2.7 extends Moore’s (1995) requirement for public value to be assessed in terms of both the clients and the general citizenry by adding levels. However, the ION literature did not progress the concept of story-making as a source of public value, perhaps due to the inherent assumptions shared with the PPI literature. The ION literature too accepts an evidence base as the primary way to improve effectiveness and attract funding, even though the definition of wicked problems means that effects in an interconnected system cannot be fully traced. Even within the terms of its own debate, a recent bibliometric analysis noted “existing network outcome research has not paid much attention to the assessment of network effectiveness at the network level, despite the

fact that Provan and Milward (2001) had noted this research gap more than a decade ago” (Hu, Khosa, Kapucu, 2016, p. 607). In addition, this debate is dominated by the professionals’ agenda, even where the subject is **public** value. This thesis thus carries forward the approach detailed in Figure 2.7, but continues to use the idea of value, rather than effectiveness, as one way of holding open an enhanced role for the public, and more equal treatment of a public agenda.

**2.5 Limitations of the literatures**

As shown in Figure 2.8, this section details the limitations of the existing PPI and ION literatures, which make the involvement of general citizens with an ION difficult to examine. This section, then, establishes the case for a new framework that links PPI and IONs.

**Figure 2.8 Key limitations in the literatures**



### 2.5.1 Limitations of the PPI literature

Following the bottom left hand box in Figure 2.8, this section details the limitations of using the existing PPI literature to study the involvement of a general citizen with an ION. It looks at the lack of categorisation of context; the absence of a narrative for involving citizens who don't bring specific, experiential knowledge of a problem; and the fact that PPI has not been viewed as a specific form of collaboration.

There was widespread acknowledgement in the PPI literature of the importance of context (for example Evans *et al.*, 2014 and Staley, 2009). Evans *et al.* (2014) reported that context dependency is what makes it hard to either “judge the quality of the evidence or draw general conclusions” (Evans *et al.*, 2014, p. 1). It has led to reports of PPI research being dismissed as anecdotal (Staley, 2015). However, for all the recognition of its importance, there was remarkably little detailed exploration of context in the PPI literature. Broadly, studies defined PPI as occurring in research (Brett *et al.*, 2014), health services (Mockford *et al.*, 2012), commissioning (Evans *et al.*, 2013), or policy (Conklin, Morris and Nolte, 2012). Some defined the geographical location, or the institution type, such as university or health care provider (as in the typology in Oliver *et al.*, 2008). Perhaps because the categories of context were so broad, the findings across different contexts were remarkably similar.

Where context has been explored more thoroughly, an explicitly realist approach has been adopted. For Pawson and Tilley (1997) it is the examination and understanding of context that allows individual case studies (evaluations in their work) to “cumulate” (Pawson and Tilley, 1997, p. 115) or, in other words, to be linked and built into generalisable theory. Unusually, Evans *et al.* (2014) took cognisance of context. First, they used Pawson and Tilley's (1997) explanation of context as having at least four layers: the capacities of the individual, the relationships between the individuals; the setting; and the wider system. Understanding the makeup of context is particularly helpful as one of the key difficulties with using the realist evaluation approach is separating contextual factors from generative mechanisms. Second, Evans *et al.* (2014) built on the findings of two extensive literature reviews. In this sense the authors were firmly



inside the critical realist tradition of adapting previous knowledge in order to deepen understanding (Bhaskar, 1975). Unfortunately, this approach appeared to be rare in the PPI field, and the problem was not limited to the explorations of context. For example, authors such as Rowe and Frewer (2005) recognised the issues that different definitions, labels and understandings have caused, but did not participate in the resolution by explicitly building their definitions and typology on existing work. It is not that different views are not welcome, it is that without integration there is no knowledge accumulation (Rousseau, Manning and Denyer, 2008).

The incomplete focus on context meant that although PPI studies have taken place in networks, for example Thompson's (2009) study of involvement in the Cancer Research Network, they did not explore the nature of IONs as a context for PPI. This is even more surprising, given that studies tell us that the impact of PPI is highly context dependent (Evans *et al.*, 2014). The network setting could have been categorised according to ION typologies, for example. This lack of categorisation impedes comparison between different organisation types as contexts for PPI, and thus theory generation and knowledge accumulation.

The second major limitation in the PPI literature for the purposes of this thesis was the absence of a rationale for involving the general citizen. Within health research the involved public contributor tends to have either direct (as a patient) or indirect (as a carer), lived experience of the condition under study. In health services the involvement is about users or clients of the service, or their carers and families. More generally (for example in the deliberative democracy tradition), involvement is of stakeholders. However, the general citizen is a stakeholder only in the very broadest sense. This sense was used in the ION literature where the general citizen was the ultimate funder of the programmes and also part of the community benefiting (Provan and Millward, 2001). In the PPI literature, on the other hand, public contributors were only found playing narrow roles as purveyors of lived experience. In turn, this meant that the only exploration of their legitimacy was in terms of the value of lay knowledge in opposition to medical-scientific knowledge (Thompson, 2009). For this thesis there are unanswered questions in relation to the role a tax-paying, general citizen beneficiary will or can play as a public contributor. There are unanswered questions concerning whether the involvement mandate from

government provides sufficient legitimacy to sustain these general citizen public contributors in the role(s) that they play.

For the purposes of this study, the third and final problem with the PPI literature was that involvement has not been regarded as a form of collaboration. An attempt to involve a public contributor is an attempt to collaborate with them. Once public involvement is viewed as a collaboration, then other literatures on collaboration become accessible for PPI studies. For this thesis, the literature on collaboration in IONs has been used.

### **2.5.2 Limitations of the ION literature**

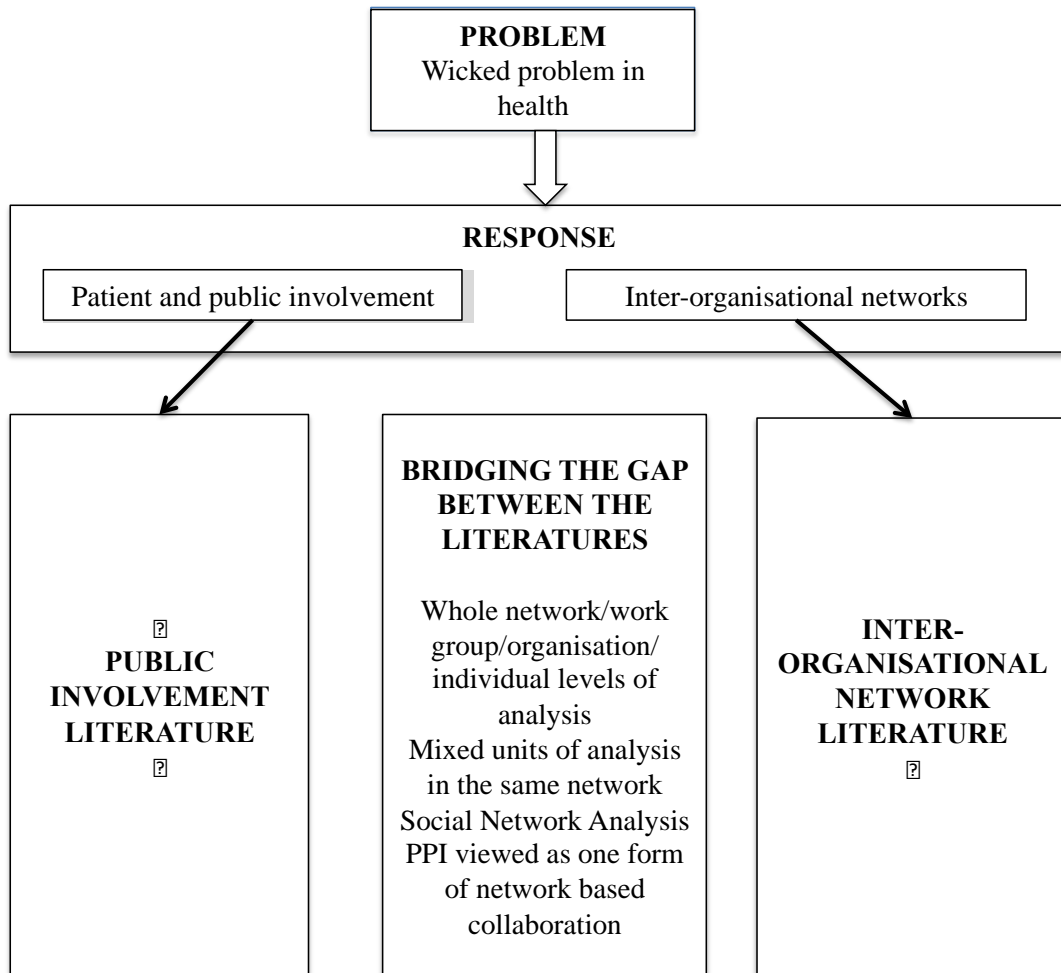
Moving to the bottom right hand box in Figure 2.8, this section assesses the key limitation of the ION literature for the purposes of this thesis. This literature review has already detailed the way that several ION authors (Weber and Khademian, 2008; Ferlie *et al.*, 2011, Bryson, Crosby and Stone, 2006) have linked the network response to wicked problems and collaboration on solutions with citizens. We know, from their report, that Ferlie *et al.* (2009) explored the subject of PPI less than they had intended, because they found limited evidence of it. The individual citizen disappears as a collaborator in ION analysis because the convention is that networks comprise actors at the same level. There are networks of individuals, networks of work groups and networks of organisations. Typically, in the literature, individuals and organisations are not connected together in a single network. This means that, although the ION literature encompasses knowledge on the structures and soft skills required for successful collaboration, typologies to characterise network contexts, and useful ways to think about the effectiveness of collaborations, none of this can easily be used to examine the way that individual citizens are involved with a health network. The problem is that public contributors are not part of an organisation, and thus are not part of the ION.

## **2.6 Bridging the gap between the literatures**

The task for this section is to bridge the gap between the two literatures in such a way as to overcome their limitations. As shown in the central box in Figure 2.9, this

section sets out three ideas to bridge the gap between the PPI and ION literatures. First, using a multi-level approach to IONs allows study at the whole network, organisation, work group and individual levels. Second, adapting block modelling means that organisations can be thought of as blocks of individuals. Public contributors, in this view, are then individuals who are not part of any block but who nonetheless may have links to individual professionals who are part of those blocks. Third, SNA can then be used to map the network of connections between public contributors and individual professionals arranged into blocks (or organisations).

**Figure 2.9 Bridging the gap between the literatures**



**2.6.1 Levels of analysis and mixed unit networks**

This chapter has already introduced the idea of using multi-level perspectives, albeit in a limited manner. Figure 2.7 shows how effectiveness can be considered at five

different levels. The public contributor can be seen at the individual level and as part of the community that should benefit from the effective functioning of the ION. However, using multiple levels of analysis for judging effectiveness offers only a small amount of assistance to this study. To bridge the gap between the literatures, the multiple levels need to be applied to network structure and functioning as well.

In their literature review, Brass *et al.* (2004) recognised that each level of a network is embedded in and affected by each higher level, so that the connections between individuals are affected by those between the organisations that provide their context. Huxham and Vangen (2005) went further, they used the individual, organisation and network level for each of the collaborative characteristics they studied. In their terms, the behaviour and approach of health sector professionals were likely to be the result of interplay between their own individual characteristics, those of their organisation, and of the network itself. Employees do not just represent their employers: they may not have thought about the organisation's purpose in joining the network, they may belong to more than one organisation relevant to the network, or the organisation may have made no additional commitment to the network other than to send the employee to meetings. Thus there is an individual level in a network, and there is a continuum in terms of whether and to what extent that individual is also the representative of an organisation. The importance of the individual level can be under no doubt: relationships between organisations in networks are vulnerable when key individuals leave (Brass *et al.*, 2004; Huxham and Vangen, 2005).

What holds at one network level also holds at other levels. In a study of social networks, Burt (2010) stated, "consistent network theory across levels of analysis is attractive because the consistency is a bridge for analogies between otherwise disparate research results, which is all the more powerful because disparate research results are likely to have complementary strength if the results can be compared in a meaningful way." (Burt, 2010, no page). Burt reported, for example, that the returns from brokerage (where an actor makes connections between two otherwise unconnected networks) are consistently positive for both interpersonal networks and IONs. Similarly, Burt also found that the returns to brokerage for indirect connections across gaps in networks followed the same pattern, although the results

were at a different scale. When network behaviours and results are consistent across different network levels, then there can be no objection to mixed actor units (in this case individuals and organisations) within the same network.

The technique of block-modelling also helps to justify a mixed unit network. Structurally equivalent actors (those with connections to the same other actors) in a network were grouped together in blocks for analysis of a block-model hypothesis (White, Boorman and Breiger, 1976). Conway (1994) used this idea to map innovation networks where the actors were either individuals or individuals grouped into blocks representing work units or organisations. In this way, mixed actor types can be considered in the same network. For PPI in an ION, then, a network of individuals could be considered and where the individuals are in the same organisation, they can be considered as a block of individuals representing (to a greater or lesser extent) that organisation. Thus the network structure and functioning of a network of individuals, some of whom are grouped together into organisations, can be studied using analytical tools from the networking literature to view PPI as one form of network-based collaboration.

Multiple levels of analysis, consistency across the levels of analysis, and the ability to regard a network as consisting of individuals some of whom are clustered into organisational blocks aids the building of the conceptual framework. As long as the conceptual variables can be applied to individuals, then they can be applied to networks of individuals some of whom are grouped together into blocks.

### **2.6.2 SNA and PPI**

Once the importance of the network between individuals is recognised, then mapping the connections between individuals could be a way to elicit valuable information about the extent of the involvement. Social Network Analysis (SNA) is an established technique, and has been called “the single most valuable conceptual tool available to network evaluators” (Popp *et al.*, 2014, p. 82). ). In this section, the term network is being used as a unit of analysis rather than to describe an organisational entity (see section 2.3.3 for the difference). In the recent business and management literature SNA denotes attempts to elicit, map and draw conclusions

about the links between actors and the content that flows over those links (Monaghan, Lavelle and Gunnigle, 2017). SNA can be quantitative, revealing network structure, or qualitative, revealing the “process, content and context of relationships and interactions” (Conway, 2014, p. 108).

The business and management literature puts SNA to varied use. For example, a database search of scholarly articles from 2014-18 (and excluding social media networks) demonstrated SNA’s use in multiple sectors (construction, finance, oil, advertising, fitness, consultancy, wine, public policy and administration, tobacco, research, conservation, cosmetics, film and television, music, agriculture, sport, tourism, real estate, IT, education, biotech, hospitality, health and politics), functions (human resource management, marketing, supply chain, sales) and topics (knowledge management and learning, workplace behaviour, innovation, creativity, governance, mergers and acquisitions, friendship, collaboration, conflict management, power, trust, performance, and social change). This list illustrates the enthusiastic application of SNA. There are, however, warning notes. In particular Conway (2014) pointed out dangers, in ethics (where individuals may be identifiable), in the data (which may be partial) and in the graphical depiction, the network maps. While maps are a common output of SNA, they can be misleading and little is known about how they are interpreted.

The extent to which Conway’s (2014) warnings have been heeded in work relevant to this thesis can be explored further. The search results showed an overlap between the business and management and the health literatures, in the form of four SNA studies in health. These studies can be categorised according to Monaghan, Lavelle and Gunnigle’s (2017) system as whole networks, dyads, or ego networks (where the connections of a single node are examined). Of the four articles, three were whole networks, and one an ego network. Table 2.4 and Table 2.5 provide a summary of the four studies and a snapshot of the way SNA has been applied since 2014. These four articles alone illustrate the wide range of approach and purpose contained under the term SNA.

**Table 2.4 SNA in whole network studies**

Paper	Summary	Method
Barron, Scarlett-Ferguson, Aspen (2015)	<p>Shows how a research grant and associated events affected the knowledge sharing and collaboration amongst grant recipients.</p> <p>Recommends using maps for “network engineering” (p. 35) using central, well-connected nodes.</p> <p>Assumes that the network structure is enduring.</p>	<p>Online survey with questions related to relationships and collaborations.</p> <p>The nodes were individual participants who chose names from a researcher-generated list to indicate which other nodes they were linked to. Participants selected relationship and collaboration types from fixed lists to show what flows over the connections. Resultant mapping shows the job type of the individual, and how connected they are before and after knowledge sharing events.</p>
Wang (2015)	<p>Network maps showed the “knowledge distribution and author factions” (p. 35) in the literature on quality in healthcare. It is unclear how the SNA was used to draw the conclusions.</p>	<p>Co-citation analysis to develop a virtual social network of researchers in health care quality. Network maps show authors as nodes with links between them. The length of the link is used to show how close their ideas are perceived to be by the authors that cite them.</p>

Paper	Summary	Method
Ekker (2016)	Computer-based emergency response training simulation tool showing links between emergency responders in different agencies and across a national border. The paper does not draw any conclusions about the network or the linkages from the SNA.	Data collected from a computer-based training simulation show the pattern of giving and receiving information. The organisations are the nodes and the labels indicate the geographical location of the node. The direction of the arrows on the links show which nodes requested information in the first map, and which nodes gave information in the second map.

**Table 2.5 SNA in ego network studies**

Paper	Summary	Method
Kothari <i>et al.</i> , 2014	Used network maps as an aid to practitioner reflection on their own practice. The findings suggested that practitioners considered the maps useful tools for strategic network planning, or as a discussion aid. No acknowledgement of the limitations of SNA.	The individual participants were asked to name six contacts as nodes they were linked to. Participants ranked their connections against two different scales and consider how likely their connections were to connect with each other. Participants were sent their own maps ready for a group discussion. A follow up interview established whether the practitioners had taken action afterwards.

It is clear that Conway's (2014) warnings about the limitations of network maps and the way they may be interpreted have not been heeded. None of the four articles acknowledged that the network maps represent depictions of SNA that may be misleading. In particular, none acknowledged the issue of "temporal grouping" (Conway, 2014, p. 105) where time-limited connections that may not have been



simultaneous are shown on network maps as if they are both permanent and co-existent. In two cases (Wang, 2015 and Ekker, 2016) it is hard to avoid the conclusion that quantitative network data has been collected and presented because a computer database makes it possible, rather than because the SNA leads to meaningful conclusions.

Although three of the four studies purport to deliver whole network maps, only one (Baron, Scarlett-Ferguson and Aspen, 2015) contained any discussion of the difficulty in achieving a whole network analysis. Barron, Scarlett-Ferguson and Aspen (2015) received a 76.5% response rate to their survey, which while a good for other purposes, is short of complete for a whole network analysis. While the authors state that no important connections were omitted, it is not clear how they reached this conclusion.

The extent to which a whole network study is possible is anyway contested, “the search for an exhaustive network is illusory” (Charbonneau and Bidart, 2011, p. 269). Rather, network boundaries are imposed by the researcher, and the inclusion criteria should be clearly stated (Conway and Steward, 1998). The omissions in the four articles here, appear to be widespread. A review of networks in public administration stated, “very few authors clearly define the network under study, its boundaries or other important properties” (Lecy, Mergel and Schmitz, 2014).

The array of purposes SNA has been put to, suggests that there are no barriers to using it to explore PPI, although no existing literature appears to do this. Thoughtfully applied, the technique seems to offer an effective route to studying the extent to which the public have been involved. Public contributors can clearly be considered as actors in a social network. The aim would not be to map the links around an egocentric public contributor (Bidart and Charbonneau, 2011), rather to map the links between the public contributors and the professionals who are working together. Questions could then be asked about the nature of the ties between these individuals (Marsden, 1990). As Milward and Provan stated “links in a network are one way that scholars can compare networks in similar or different policy domains” (Milward and Provan, 1998, p. 387).

The use of SNA needs to be re-purposed for public involvement, though. Typically, social network structures are related to individual attributes such as advantage in terms of pay and workplace evaluations (Burt, 2010), job-finding or gaining promotion (Brass *et al.*, 2004). In PPI, it is not clear that there is the same degree of externally measurable advantage: citizens will not be promoted or receive pay rises as a result of their involvement. Public contributors have reported both positive personal outcomes from PPI and payment as a reward from involvement (Staley, 2009). Despite payment being regarded as best practice (University of the West of England, 2011), not all involvement opportunities offer payment (for example, in Evans *et al.*, 2014 only two out of eight cases offered monetary payment). Even where payment is offered, and is seen as a positive outcome, pay rises are not either the individual ‘advantage’ that is sought from citizen involvement (Evans *et al.*, 2014) nor is payment linked to the ‘performance’ of the citizen through rankings or evaluations and cannot be related to the citizen’s position in a network map.

If citizens are mandated a place at the table, but collaboration is not assured, then simply mapping the network without relating network position to individual advantage still offers insight that other analytical tools do not. Interviews, observation and document review can all demonstrate what happens when citizens take their places at the table. But mapping the number, strength, frequency and content of relations between team members (including the public contributors) could be used to demonstrate whether the work is getting done with the public involved, or by the other project team members once the public has left the room. In this way, SNA and mapping can be used as an indicator of the extent to which the citizen has really been involved in the work.

### **2.6.3 The citizen as part of an ION**

Because this chapter has established a way for individual public contributors (not just individual network managers or employees) to be regarded as part of the ION, PPI can be viewed through the lens of network-based collaboration. That is, PPI can now be viewed as one particular form of collaboration, allowing the research on what works for collaborations in a network to be brought to bear on PPI.

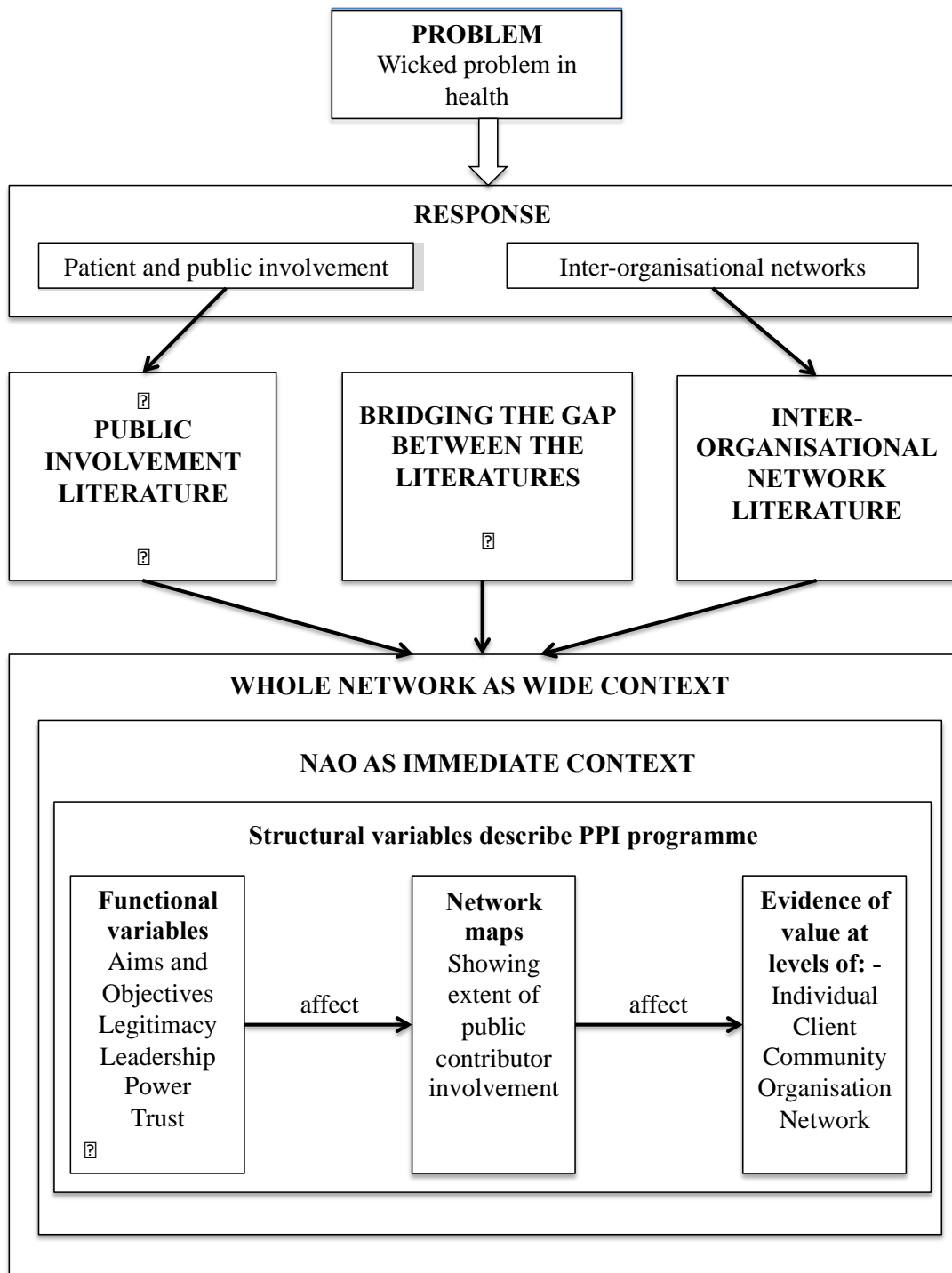
The management of tensions can be expected to be as important for PPI as it is for other forms of collaboration. Following Huxham and Vangen (2005), it is the reason there are no simple prescriptions for how to involve the public. There is not one right answer that applies to every project, or even one that applies throughout a single project. This leads on to the view that collaboration is hard. Although policy makers see collaboration as a response to wicked problems, the advice from Huxham and Vangen (2005) is “don’t do it unless you have to” (Huxham and Vangen, 2005, p. 37). When both public involvement and the ION are mandated, the attempt at collaboration is inescapable. So although collaboration is hard, the theory can help practitioners understand the tensions involved in order to manage them (Huxham and Vangen, 2005). Thus, network-based theories of collaboration could help the PPI literature to move away from simple prescriptions such as: successful PPI requires alignment of goals and purpose, or successful PPI requires trust from the beginning.

In policy formation and in the PPI literature there was little acknowledgement of the difficulties of collaboration. Most papers reported overall positive experiences. This was attributed to the fact that those who are hostile to involvement do not write about it (Pollard and Evans, 2013), and to publication bias (Brett *et al.*, 2014). In a rare reflection on the downsides of involving the public in research, Pollard and Evans (2013) concluded that a more honest dialogue would be helpful. Considering PPI as one type of network-based collaboration allows the difficulties to be examined in more detail. The complaints about involvement that are expressed in the PPI literature are: involvement takes more time and is harder than professionals anticipated (Evans *et al.*, 2013); and although involvement leads to improved quality, it increases cost and the workload on the professional (Pollard and Evans, 2013; Staley, 2009). However, a much bigger set of collaboration challenges are reported in the ION literature: goal congruence and commitment; managing different cultures; reduced autonomy; the time and effort to coordinate and to build trust; barriers to achieving the network’s aims; managing the complexity; balancing unequal power; resolving conflict; and lack of organisational capacity to cope with the extra workload (Popp *et al.*, 2014). This longer list of complaints about the difficulties of network collaborations could reflect a more mature literature, the study of sectors outside health, or that network collaborators feel more able to

acknowledge the difficulties than, for example, researchers whose funding relies on some public involvement.

Because collaboration is hard, and involves managing tensions, the network literature argued that the work is never done. “We suggest that the ability to reap the benefits of networks, especially when they are mandated, is in large part based on paying careful attention to nurturing the component parts of collaborative capacity” (Popp and Casebeer, 2015, p. 231). For Popp and Casebeer (2015), collaborative capacity was made up of the building blocks of: legitimacy, shared risk, trust, resources, goals and vision. For Huxham and Vangen (2005) the components were: aims, purpose, structure and dynamics, trust, power, identity and leadership. The ION literature thus presented variables which can become part of the set of functional variables being compiled in this thesis. Those variables that apply throughout all the network levels, and which resonate with the themes in the PPI literature, can be added to the functional variables in the framework being built here. The variables that seem to relate most of all to the way PPI functions are aims and objectives, legitimacy (due its importance for mandated collaborations), trust, power and leadership. Figure 2.10 shows this set of functional variables in the final framework.

**Figure 2.10 A new conceptual framework**



## 2.7 The framework

The conceptual framework in Figure 2.10 shows PPI as one form of network-based collaboration. Beginning with the whole network as wide context, this section of the thesis presents each of the elements of the conceptual framework in turn. The focus is on using the theory and structure-rich network collaboration literature to examine

the relations between actors when general citizens are involved with a health network.

### **2.7.1 The whole network as wide context**

The idea that the health network provides a categorisable context for public involvement should be of broad use given that, as policy initiatives, public involvement and health networks are used as parallel responses to wicked health problems. For example, Ferlie *et al.*'s (2011) study of networks found evidence of at least the intent to involve the public in all of the four network types studied. The ION literature can thus inform the conception of context for public involvement in the following ways. First, typologies categorise and compare different network contexts and second, theories to show the ways in which a network provides a different context for public involvement than other organisation forms. For this thesis, member organisations comprised the whole network or the wide context. These autonomous, formal members of the network participated to meet a range of objectives set by NHS England. The wide context could thus be characterised as stable, complex, resourced and heterogeneous.

### **2.7.2 The NAO as immediate context**

The immediate context for PPI can be classified as a mandated NAO. The ION literature contains conflicting expectations about the influence of an NAO on PPI. On one hand, IONs might provide a more benign context for PPI than single organisations. To set up and run a network, the staff should already have developed the habits that nurture collaborative capacity. On the other hand, a mandated, NAO-led network is seen in the literature as close to a single entity on a continuum of organisational forms. Thus the staff of an NAO might deploy a command and control style. In either case, the immediate context may not be the most influential element in determining the success of public involvement. Evans *et al.* (2014) found throughout their study that context, structure and process are less important for the success of PPI than leadership and interpersonal relationships.

### 2.7.3 Structural variables

The structural variables can be used to describe a PPI programme. The structural variables capture the formal intent of an organisation towards its PPI, in the form of policies, processes, and agreed practices. The structural variables represent the deliberate choices the organisation has made for its PPI programme. They can be used to compare the intent of PPI programmes in different contexts. Their use should promote knowledge accumulation in PPI. The variables accreted during the literature review, sorted into approximate order in the involvement process, are shown in Table 2.6.

**Table 2.6 The structural variables**

<b>Structural variable</b>	<b>Association with effective PPI</b>	<b>Sources</b>
Who initiates the involvement?	A strong role given to the other party, rather than the motivations of one party dominating the involvement.	Arnstein (1969); Pretty (1995) Farrington and Bebbington (1993); Oliver <i>et al.</i> (2008); Gibson <i>et al.</i> (2012)
Who is involved?	Involvement of a diverse population, selected for the purpose.	Staley (2009) Rowe and Frewer (2005)
Diversity of mechanisms	Allow diverse groups to be involved.	Gibson, Britten and Lynch (2012)
Critical mass of public	Public contributors have peer support.	Evans <i>et al.</i> (2013)
Clear role definition	Public contributors and staff understand public's contribution.	Evans <i>et al.</i> (2013)
Budget	Funds are available to support involvement.	Brett <i>et al.</i> (2014)
Involvement reactive or proactive.	Permanently in place involvement (i.e. proactive).	Tritter (2009)
Public contributors supported to meet together regularly	Public contributors are supported in order to be effective.	Crepaz-Keay (2014)
Public contributors offered payment for their time	Public contributors are supported and valued.	Crepaz-Keay (2014)

<b>Structural variable</b>	<b>Association with effective PPI</b>	<b>Sources</b>
Training for public contributors	To allow the public to develop expertise, if they wish to. Training denotes support for public contributors to be effective.	Brett <i>et al.</i> (2014); Staley (2009); Evans <i>et al.</i> (2013); Crepaz-Keay (2014)
PPI led by a paid public contributor	To give public contributors access to decision making.	Crepaz-Keay (2014)
Public contributors on governing body	To give public contributors access to decision making.	Crepaz-Keay (2014)
Face-to-face involvement	To minimise the loss of any information flowing.	Rowe and Frewer (2005)
Facilitation	To minimise the loss of any information flowing and promote dialogue.	Rowe and Frewer (2005); Li <i>et al.</i> (2015); Evans <i>et al.</i> (2013)
Depth of the interaction	Profound interactions.	Farrington and Bebbington (1993)
Scope of the subject matter	Across a wide scope.	Farrington and Bebbington (1993)
Consistent set of managers	Aids relationship building.	Evans <i>et al.</i> (2013)
Involvement from the beginning.	More scope to influence the agenda at the beginning.	Brett <i>et al.</i> (2014); Evans <i>et al.</i> (2013)
Involvement all the way through.	Regular, rather than sporadic involvement.	Staley (2009)
Information flow	Two-way leads to dialogue and changed understanding.	Rowe and Frewer (2005)
Public members contribute to official information	Demonstrates public contributor influence.	Crepaz-Keay (2014)
New initiatives are co-designed or co-produced	Demonstrates public contributor influence.	Crepaz-Keay (2014)

#### **2.7.4 Functional variables**

In the conceptual framework, the structural variables are used to demonstrate the organisational intent of the PPI programme. The functional variables, on the other hand, show how the programme really happened behind the closed doors of individual project meetings. The functional variables have not been deliberately selected in advance by the involving organisation. The functional variables are set



out in abstract terms so that they can be used to capture how the involvement operated. While the ION literature showed both structure and functioning as affecting value, the PPI literature has tested some elements of whether structure or functioning is more important, and found in favour of functioning (Evans *et al.*, 2014 and Oliver *et al.*, 2008). In this thesis, functional variables are proposed to have more affect on the extent of the involvement and the value attributable to it. For this reason, the functional variables are set out in more detail in the following sub-sections. The functional variables that appeared in both the ION and PPI literatures, and which can be applied to both the individual and organisation levels are summarised in Table 2.7 and detailed in the following sub-sections.

**Table 2.7 The functional variables**

<b>Functional</b>	<b>Association with effective PPI</b>	<b>Sources</b>
Aims and objectives	Managed tensions between members throughout. The start is important. Homogeneity makes collaboration easier. Individuals bring own aims, as well as organisations'. People outside have aims for it. Aims can be implicit, explicit, hidden or false.	White (1996); Bryson, Crosby and Stone (2006); Popp <i>et al.</i> (2014); Huxham and Vangen (2005)
Leadership	A positive attitude or at least openness. Feedback to the contributors. Allowing time for PPI. Management of inclusion versus speed. Constant management of the tensions. Assessment of training needs. Sensitive assignment of workload. Listening. Organising and facilitating. Setting up a relaxed and inclusive environment. Communication, persuasion and motivation. Includes negotiation, boundary spanning, teaching, coaching and mentoring.	Brett <i>et al.</i> (2014); Evans <i>et al.</i> (2014); Evans <i>et al.</i> (2013); Popp <i>et al.</i> (2014); Huxham and Vangen (2005); Pollard and Evans (2013); Wilson <i>et al.</i> (2015); Ferlie <i>et al.</i> (2009)
Legitimacy	Experience-based. Mandated. Internal and external. Based on representativeness. The issue of professionalisation of the public. The impact legitimacy has on the role the public play. Discursive.	Li <i>et al.</i> (2015); Ferlie <i>et al.</i> (2009); Popp and Casebeer (2014); Popp <i>et al.</i> (2014); Thompson <i>et al.</i> (2012); Purdy (2012)

Functional	Association with effective PPI	Sources
Power	Power over decisions and agenda. Organisational willingness to change. Relationships to outside power structures. Public contributors are not powerless. Link to the management structure. Ways to reduce the power imbalance. Power can be exercised, shared, or used altruistically. Points of power and the way they shift through every interaction. The power of absent entities. Power at the different levels and circuits of power.	Arnstein (1969); Pretty (1995); White (1996); Tritter (2009); Gibson, Britten and Lynch (2012); Evans <i>et al.</i> (2013); Staley (2009); Huxham and Vangen, 2005; Clegg (1989); Ferlie <i>et al.</i> (2013)
Trust	Trust between individuals. Expectation of reciprocity. Requires constant building and rebuilding. Association with closed networks.	Brett <i>et al.</i> (2014); Popp <i>et al.</i> (2014); Burt (2010); Huxham and Vangan (2005).

### 2.7.5 Functional variables - aims and objectives

In this thesis aims embody the overall intent of an endeavour, while objectives are the specific tactics. Compared with the ION literature, the treatment of aims and objectives in the PPI literature is limited. This treatment is embodied in Wilson *et al.*'s (2015) finding that one of the things necessary for PPI to have positive outcomes and impact is “the researchers and lay representatives having a shared understanding of the moral and methodological purpose of PPI” (Wilson *et al.*, 2015, p. 6). Underlying this seems to be the assumption that the professional members of a project already share this understanding between themselves. All that remains is to agree this with the public contributors. However, where the ION is tasked with responding to wicked problems, there can be no simple agreement over the aims and objectives. In an ION there is anyway a “goals paradox” (Popp *et al.*, 2014, p. 52) meaning that the actors in a network need goals that are similar enough for successful collaboration but yet sufficiently different to create a distinct advantage from collaborating. In network collaboration, and in PPI, the point of collaborating is to harness diversity. Simple agreement on aims and objectives that lasts through a project will be elusive.

Even if the projects involving the public are not focused squarely on the wicked problem, then agreeing aims and objectives is still problematic. It is not just that each individual (including the public) will have different personal aims, but that each organisation will have varying aims, and that all of these are different again from the aims of the collaboration. As Huxham and Vangen (2005) suggested there is still more complexity. The aims of actors outside the network may be important (for example, government or funders). These aims may be explicit, implicit, actively hidden or even false because “they may be a way of masking what may be seen as unacceptable reasons for collaborating or indeed apathy to the collaborative agenda” (Huxham and Vangen, 2005, p. 88). This is exemplified in PPI by reported differences between what researchers say about involving the public, and what they actually do (Pollard and Evans, 2013). Furthermore, the aims may change over time.

Huxham and Vangen (2005) suggested a number of practical approaches. One was to set out all the aims. This would not expose every aim (for example, hidden, or false ones). As the aims would change over time, this exercise would not remain current. However, the process of appreciating the different viewpoints could be helpful to practitioners and to the process of collaborating. Alternatively, Huxham and Vangen (2005) suggested not waiting for complete agreement, but starting work on what could be agreed. This start would have the potential to become a virtuous cycle where working together built trust, which created more common aims that could be worked upon. The work to find and build on some aims that can be agreed would last throughout the project.

#### **2.7.6 Functional variables - legitimacy**

The narrative supporting the public’s involvement in health services and research tended to be located around their lived experience of a particular condition, either as a patient or as a carer. For health researchers, the public’s experiential expertise was seen as the key reason for their involvement (Thompson, 2009). And yet, there are problems with this narrative even as it applies to health research. The experiential knowledge of the patient was supposed to provide a different knowledge in a team of professionals. It was supposed to be a voice that added pluralism and balance to the views of the professionals (Thompson, 2009). Yet some professionals did not

believe in the value of experiential knowledge (Pollard and Evans, 2013).

Thompson (2009) found that involved members of the public sought training (in science, medicine and research), believing that this training conferred additional credibility and allowed them to converse with professionals in their own language. Thus public contributors adapted to take part in the medical-scientific debate, rather than changing the terms of that debate. To further complicate the issue of public contributor legitimacy, Thompson *et al.* (2012) reported that researchers believed that the more professionalised public contributors became, the less credibility, authenticity (and by extension, legitimacy) they had.

For some researchers, public contributors were legitimate only if they were either representative of (Li *et al.*, 2015), or very in touch with a patient group (Wilson *et al.*, 2015). In this view of legitimacy a public contributor should not only possess lived experience of a condition, but should also be representative of others with that condition. The literature described a “double standard” (Martin, 2008, p. 1760) in PPI where structures permit only a small number of selected public contributors whom professionals are then able to denigrate as unrepresentative (both democratically and statistically) when they offer views on behalf of a patient group and again as unable to move away from their own situation when they share personal stories. Martin (2008) characterised legitimacy in PPI as a negotiation over representativeness and found that professionals attributed representative legitimacy to those with lived experience and those providing a lay view to contrast with a professional medical one. Public contributors themselves saw the deployment of their full set of knowledge and skills as an additional source of representative legitimacy.

For Brett *et al.* (2014) the public’s role needed to be clearly defined in advance in order to be successful, although in the negotiation over legitimacy described above this would give professionals the upper hand. However, Evans *et al.* (2014) found that leaving role definition hazy at first seemed to work. Once work was under way, the roles of the public contributors evolved, and this evolution could be linked to the process of negotiating legitimacy.

The ION literature adds the presence of a mandate to the discussion of legitimacy. Public involvement is a government aim and is enacted through funder requirements. Public contributors in research, health service delivery, and in health projects all shared a government mandate, which the ION literature showed as likely to confer only external legitimacy. The mandate may even undermine internal legitimacy, especially if the relationships between actors did not exist before the mandate (Popp and Casebeer, 2015). Without existing relationships to draw on, the citizen was likely to need additional sources of internal legitimacy. These sources of legitimacy were likely to inform the role the public contributor plays in a project.

The ION literature also showed that legitimacy is an issue for all the actors in a network, not just the public contributors. An ION must demonstrate that its existence and funding is worthwhile, in terms of meeting its objectives and delivering outcomes that its members, alone or connected in a different way, could not. The organisations involved in any project must similarly demonstrate that they bring something essential to the project. Purdy (2012) saw legitimacy as a source of power, conferring status and permitting more frequent, more monopolistic communication within a collaboration. For Purdy (2012), even participants who lacked other sources of power could use “discursive legitimacy” (Purdy, 2012, p. 411). Discursive legitimacy was strong where the participant spoke and acted in accordance with widely held values and where they were seen as representative. Public contributors in this thesis might be able to make some claim for discursive legitimacy from widely shared values, but being seen as representative is problematic. Following Cornwall’s (2008) logic, even where public contributors are selected on the basis of experience with a condition, there is no guarantee that this identification will resonate with the individual, or that people who share that condition will necessarily share a broad set of interests. The ION literature showed that all the participants in a collaboration must develop a basis for legitimacy, and suggested discursive legitimacy as one possibility that could be adopted by the general citizen.

### 2.7.7 Functional variables - leadership

In the PPI literature there was evidence that the relationships between people were more important than the structure or processes of involvement. Staff members needed to be able to assess the public's skills and arrange training, to understand how much the public wanted to be involved and assign workload, to check if they were being overwhelmed and support them (Pollard and Evans, 2013). Wilson *et al.* (2015a) said, "the strongest theme to emerge from our data was the centrality of relationships" (Wilson *et al.*, 2015a, p. 126). They suggested that these relationships took time, must be two way, developed better in some contexts, and required skills to build. This relational work seemed to have the most impact when done by senior people. For example "senior management ownership of involvement is critical" (Evans *et al.*, 2013). Evans *et al.* (2014) called this relational work by senior people leadership because it could be done by the project manager or delegated by them to someone senior (as long as the project manager remained open to it). Leadership here means "taking responsibility for ensuring research partners were recruited and supported, making sure meetings with them were well organised and facilitated, demonstrating a relaxed and inclusive approach to relationships and good communication – listening to and acting on research partners' contributions" (Evans *et al.*, 2014, p. 46).

In ION terms, it is no surprise to find that relationships are so fundamental. Popp *et al.* (2014) said, "the study of leadership in either a network or organisational context reinforces the point that it is people who collaborate, not organisations or networks" (Popp *et al.*, 2014, p. 42). They continued, "influence, use of process and consensus building rather than authority become the main agents of change, and this means that leadership in networks can be considerably more nuanced and subtle than in traditional hierarchies" (Popp *et al.*, 2014, p. 43). The ION literature in this way predicted that leadership and management skills would be different in an ION from how they were in a hierarchy. Leaders and managers in an ION must negotiate, facilitate, manage conflict, and nurture relationships (Popp and Casebeer, 2015). The ION literature also predicted that leadership skills would be directed at managing (rather than resolving) the tensions inherent in collaborations between diverse actors (Huxham and Vangen, 2005).

In their study of health networks, Ferlie *et al.*, (2009) looked for evidence of a change to network styles of leadership. One network was classified as emergent, and the rest were mandated or contained at least some mandated element. They found a “significant shift from narrow, vertical role based models of management to broader, influence based and lateral patterns of leadership” (Ferlie *et al.*, 2009, p. 157). Of particular relevance here is what Ferlie *et al.* (2009) called a mixture of hard and soft management skills. The hard skills were observed in using national targets and measurement systems to pressure for change. The soft skills were directed at building influence. In place of having direct authority over other people, network managers had to persuade them to co-operate, which required “communication, persuasion and motivation” (Ferlie *et al.*, 2009, p. 156). The specific soft skills identified were negotiation, boundary spanning, teaching, coaching, and mentoring (Ferlie *et al.*, 2009). Ferlie *et al.*’s (2009) study did not explore a specific link between PPI and network styles of leadership. The evidence presented suggested that managers displayed network leadership styles where the involvement was marginal and where it was successful, so it did not appear to be a sufficient condition for successful PPI.

### **2.7.8 Functional variables - power**

In the PPI literature, discussions of power were focused on reducing the power inequality between health sector professionals and the public contributors (Evans *et al.*, 2014). Studies found that good interpersonal skills, used to make the public contributors feel valued (Evans *et al.*, 2014), and good meeting management (Wilson *et al.*, 2015) had an effect. Reducing the power imbalance was seen to be important in PPI because otherwise the involvement could seem tokenistic, and the public may not really have been included (Pollard and Evans, 2013).

Some parts of the involvement literature recognised that the view of power as always tilted in favour of the health sector professionals is not the full story. By adopting the standpoint of the health professionals (in this case researchers), Pollard and Evans (2013) suggested that professionals found it hard to challenge public contributors openly and robustly in project meetings. The researchers might opt to reduce conflict with the public by producing research that satisfied the public and

the institution but not their own academic standards. Pollard and Evans (2013) also pointed out the shock felt by some public contributors and the support they needed when they realised that the research team had no power to get the results of their research adopted. This work started to recognise that both the health sector professionals and the public contributors are party to power relationships inside and outside the project team.

Wherever there are two or more actors, power is present (Popp *et al.*, 2014), so no network analysis is complete without a consideration of it. Power could be exercised for the gain of the actor, or transferred to other actors as an act of altruism or to further the aims of the collaboration (Huxham and Vangen, 2005). Power was important because of its link to trust. Power imbalance was seen as something that could erode trust (Brass *et al.*, 2004), especially as a network often brought the expectation that power would be, to some extent at least, shared (Popp *et al.*, 2014).

As a type of network collaboration, PPI carries an expectation of power sharing. From their studies of collaborations, Huxham and Vangen (2005) showed how this power sharing might be studied. First, at a network and organisation level (which Huxham and Vangen, 2005, p. 177 call the “macro level”) the sources of power might be control over resources or skills. Other sources of power, relevant to an NAO, might be formal authority or network centrality. More subtly, the collaboration might be more important to one partner than another, perhaps because one has an alternative. These sources of power are not constant over time, and the importance of each source may wax or wane depending of the lifecycle stage of the collaboration. Thus power at the macro level is dynamic rather than static.

Even more useful to this thesis is the study of power at the “micro level” (Huxham and Vangen, 2005, p. 179). Power as a functional variable is at the micro level, between individuals such as public contributors and professionals interacting during project meetings. In this context, “there is not just one ‘power baton’ that may be passed around, but a multitude of batons that are not all made of the same material” (Huxham and Vangen, 2005, p. 185). The passing of these batons, or the “transfers” (Huxham and Vangen, 2005, p. 176) of power, can happen between individuals multiple times within and between meetings over the course of a collaboration. In



interviews and meeting observations, these power transfers can be studied by attending to the “points of power” (Huxham and Vangen, 2005, p. 180) such as where meetings are held, how they are managed, how the format and agendas are determined, and what the meeting follow-up entails. Of particular interest in the context of trying to observe power in action is the idea that power also resided with those who were absent, but to whom those attending the meetings deferred. Finally, in line with the ideas from the PPI literature, public contributors should not be thought of as powerless because “within the context of any macro-level asymmetries of power ... there is a presumption that there may be many moments when power can be in the hands of the apparently less powerful” (Huxham and Vangen, 2005, p. 185).

In their book on health networks Ferlie *et al.* (2013) found Foucauldian analysis a useful explanatory tool. Although the authors did not use it to examine PPI, their work provides useful insight into the nature of power in a health network setting, and the impact on the health sector professionals. Foucault (1978) charted the link between governing for the health and well being of a population and the “development of knowledge ... of state that can be used as a tactic of government” (Foucault, 1978, p. 214). Ferlie *et al.* (2013) explored how knowledge was created in health IONs. They found that influential advisory texts turned out to have been written by a core group of “senior clinical academics” (Ferlie *et al.*, 2013, p. 212), rather than a diverse group including public contributors. The advisory texts made areas of medicine knowable and thus governable. They were evidence based and therefore seen as a legitimate form of knowledge by clinical practitioners. Clinical behaviour changed in response, not because of direct forms of control such as central reporting regimes that could be evaded. Rather, clinical behaviour changed because of indirect forms of control. For example, clinicians wished to avoid being seen as engaging in poor practice. Ferlie *et al.* (2013) also found an impact on network managers, especially those who were “clinical managerial hybrids” (Ferlie *et al.*, 2013, p. 216). These hybrid managers worked with commitment and energy, acquiring new skills to promote evidence-based quality improvement. Thus Ferlie *et al.* (2013) linked knowledge and power in health networks, and showed how the behaviour of clinicians and network managers was influenced by evidence-based knowledge.

The discussion of power now needs to link considerations of the multiple levels (individual, project, network, societal and incorporating micro and macro considerations), and the possible explanatory power of Foulcauldian analysis within a critical realist enquiry. Because “there is no coherent body of literature on power in collaborative settings” (Huxham and Vangen, 2005, p. 174), this means going beyond the PPI and ION literatures to find a framework to tie the disparate elements together. Lukes (1974) presents a possibility with a three-dimensional approach. The first dimension of power describes observable conflicts of interest resulting in decisions which demonstrate who is the most powerful at that instant, or in that arena. The second dimension of power describes observable conflicts of interest where decisions are avoided, for example by controlling which decisions are on the agenda. In this way, inaction or not making a decision can be analysed as power. The third, and most controversial dimension, describes the avoidance of conflict through impeding the realization of real interests. In this dimension not only is the conflict not observable, but the opposing interests are never formed. This third dimension carries with it the problems of identifying conflict that is not observable, and the identification of true interests if the supposed holders of those interests have not.

For Clegg (1989) there are three resolutions to the ‘problem’ of real interests. The first is by recourse to a more informed external observer with privileged access to the real interests (the Marxist approach of false consciousness lies here). The second is by using moral relativism, and taking “‘real interests’ to be a function of one’s explanatory purpose, framework and methods, which in turn have to be justified” (Lukes, 2005, p. 148). The third is by equating preferences with real interests (that is the subject understands their own preferences) although this approach also robs the concept of real interests of any explanatory power.

Based partly on his critique of Lukes, Clegg (1989) proposed an alternate, explicitly realist approach which builds in both the consideration of different levels and the possible utility of a Foulcauldian approach in the circuits of power model, shown in Figure 2.11. In the model, power is a characteristic of the relations between actors (and is thus reciprocal); and while the structure of a situation establishes a way for power to be exercised, it can be impeded. Clegg (1989) showed that the model could

be used to analyse power from the perspectives of the actor exercising it, and the actor having it exercised over them. Not only is the model relevant for individual, organisational and network actors, but Clegg (1989) showed that organisational analyses of power must include consideration of the individual through “the myriad practices which *inhibit* authorities from becoming powers” (Clegg, 1989, p. 200, italics original). In summary this realist model permits a multi-level analysis where the assessments of power from the PPI literature, and from the networks literature can be considered together.

**Figure 2.11 The Circuits of Power**

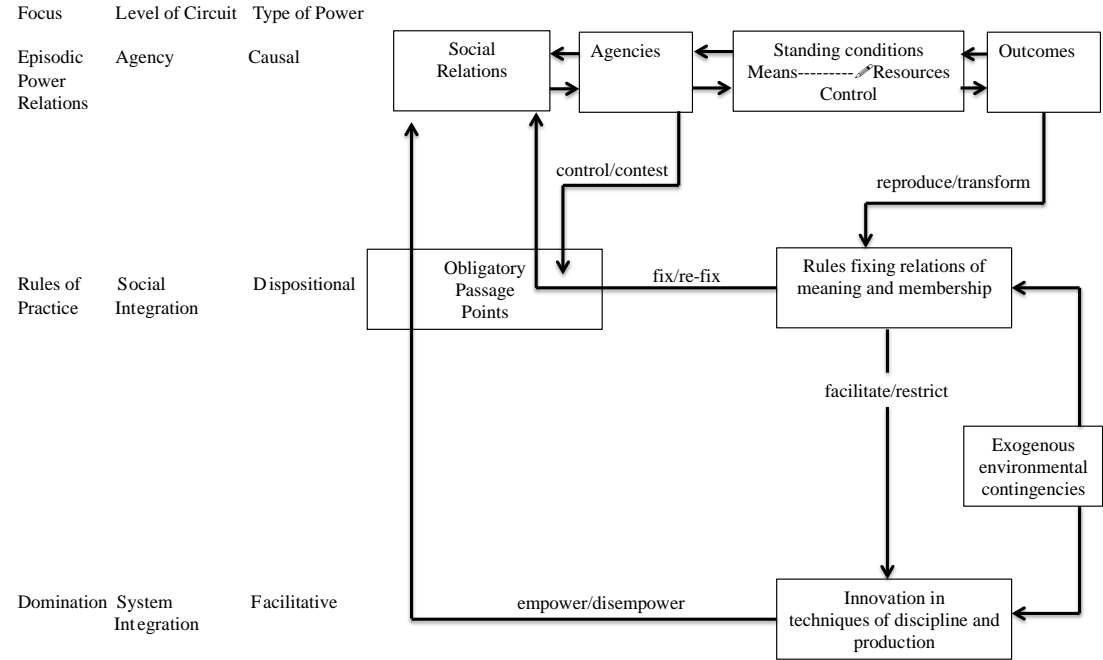


Figure 2.11 shows the Circuits of Power model (Clegg, 1989, p. 214), reproduced with permission of SAGE publishing.

Figure 2.11 accounts for both the observable “episodic power” often called “power over” (Clegg, 1989, p. 89) in which one actor causes another to do something they would not otherwise have done and for the other actor’s resistance to the exercise of power. Using the circuits of power model, observed episodes of power in PPI programmes could be placed into a wider structure. For Clegg (1989), power that is exercised purely in the top, episodic circuit is secure, unchallenged and regarded as the norm. Episodic power can be exercised without going through the other circuits,

because control over the “standing conditions” (Clegg, 1989, p. 214) is already established, and is accepted rather than challenged. This perspective illustrates why, in their study of PPI in a cancer research network, Thompson *et al.* (2012) found that public contributors did not challenge the experts, indeed the public did not see this as part of their role. The public were operating in a role, the rules of which were fixed and unchallenged. This is not to say that the public are powerless. As Huxham and Vangen (2005) showed, there are multiple points of power (and resistance) throughout any collaboration. However, all of these interactions may take place within a set of standing conditions (or context) that are themselves accepted.

The second circuit of power concerns “dispositional power” or “power to” (Clegg, 1989, p. 89). The power in this circuit is not necessarily exercised. Dispositional power is contained in the structure of things. An example is helpful here to show both how the episodic and dispositional power circuits interact, and how the model can be used at different actor levels. In an organisation, the hierarchy is a key determinant of dispositional power. Certain decisions (on resources, for example) need to go through “obligatory passage points” (Clegg, 1989, p. 214) or control points. This dispositional power, held by the organisation, forms the structure within which episodic power is played out. There is resistance to episodic power, despite the organisational hierarchy, because individuals do not always conform to the wishes of the organisation. Resistance to power in the first circuit does not mean that the overall structure or hierarchy is being challenged. This happens more rarely, and goes through the second circuit of dispositional power. Challenge here can come as a result of the outcomes from the first circuit, from external events, and as a result of changes to the obligatory passage points.

The third circuit of power brings the work of Foucault into the model, showing how environmental change and innovation can affect social relations. Ferlie *et al.*'s (2013) findings (set out earlier in this section) on the utility of Foucauldian analysis for analysing health networks indicate how this third circuit might be useful in the study of health sector IONs. Of particular interest is the link between knowledge and power. The third circuit then can be used to consider the issues of lay knowledge versus medical and technical knowledge and how power might be constructed around one or both types of knowledge. Clegg's (1989) model thus both

incorporates Lukes' (1974) assertions that power can inhibit and constrain agents in ways that are not observable and possibly remain unrecognised to the agents themselves. It also turns the three-dimensional model on its head. In the circuits of power, restricting power relations to expression in the first circuit is "the supreme achievement of power" (Clegg, 1989, p. 126). Of particular interest to this thesis will be the extent to which power and resistance are constrained to the first circuit.

### **2.7.9 Functional variables - trust**

In the PPI literature trust was seen as part of nurturing good relationships between public contributors and professionals. Longer-term relationships where the professional team did not change too much and where the public contributors were involved regularly were seen as ways to build trust (Evans *et al.*, 2014). Evans *et al.* (2014) found that incorporating informal opportunities to chat or have food helped to build trusting relationships. The key elements of trust from the networks literature were that it included the expectation of some reciprocity; it could be based on perceptions in the absence of experience working together; and in for-profit networks it was traditionally associated with a reduction in transaction costs (Popp *et al.*, 2014). There was debate about whether time and exposure to the other parties in a network necessarily led to trust (Popp *et al.*, 2014), whether trust could only be built on a cycle of successful outcomes or whether the process of successfully working together could build trust even if the outcomes were not achieved (Huxham and Vangen, 2005). There was wide agreement that trust was a building block for collaboration that requires constant nurturing (Bryson, Crosby and Stone, 2006; Huxham and Vangen, 2005).

For Huxham and Vangen (2005) trust was built in a cycle, using the "small wins approach" (Huxham and Vangen, 2005, p. 160). The cycle began with actors working together on something small, with modest aims, which reinforced trust and allowed collaboration on more ambitious tasks. They pointed out, however, that the cycle would be frequently disrupted, by external environmental change (such as changing policy initiatives or re-organisations) and that the individuals assigned to the project would also change over time, further disrupting the trust cycle. Hence the cycle did not build over time to greater and greater levels of trust, but started,

got disrupted and had to begin again. In common with other building blocks in collaborative capacity, the work to build trust continued throughout the project and was never done.

Trust can exist at multiple levels: the network level, the organisational and the individual. Brass *et al.* (2004) reported that while trust was commonly identified as between individuals, individuals could trust the organisation rather than the person they were dealing with. Trust was associated with effective networks, but also with network closure (Burt, 2010) where a small, stable group of individuals had many strong connections to each other. In this setting trust was high because the reputational risk to bad behaviour was also very high. This was a small, tightly connected group where transgressions would be quickly reported and known by all members. By contrast, public contributors are likely to be outsiders in the context of a health network. Outsiders cannot introduce new ideas to a group that does not trust them, and therefore fail to benefit when they attempt to connect disparate groups (Burt, 2010). As outsiders, public contributors are dissimilar to professionals whereas the literature tells us that similarity is important, promoting interaction, understanding, predictability, and thus trust (Brass *et al.*, 2004). For Burt the answer was simple, outsiders should “affiliate with an insider” (Burt, 2010, no page), one who was highly connected and who acted as a link between otherwise disconnected networks. The insider gives the outsider legitimacy in the group by introducing them, vouching for them, and acting with them. Involvement may be more successful if public contributors are trusted outsiders because they are affiliated with well-connected insiders.

Trust may be the most important of the functional variables for collaboration. In their study of mandated IONs with an NAO structure, Kelman, Hong and Turbitt (2013) found that only trust was associated with successful outcomes (and only then in favourable circumstances). Other collaborative practices such as reducing power imbalances and leadership practices, on the other hand, were not positively correlated with effectiveness.

Given the potential importance of trust, definitions and models from the wider literature outside PPI and IONs are instructive. This wider literature explicitly links

trust with power. Zand's definition of trust as "the conscious regulation of one's dependence on another that will vary with the task, the situation, and the other person" (Zand, 1972, p. 230) illustrates this point. Here trust is the act of increasing or reducing the power of the other person. In organisational settings, individuals are necessarily interdependent, giving them power over each other, but for Mayer, Davis and Schoorman (1995) trust is only necessary where the trustor puts themselves at risk, thus their definition of trust as "the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party" (Mayer, Davis and Schoorman, 1995, p. 712). Here trust is only necessary for collaboration where there is risk. In PPI, Yang (2005) suggested the risk the professionals take to be the opportunity cost of the resources used by involvement, and that the public may "cause trouble or find fault" (Yang, 2005, p. 276).

In their widely used model of trust, Mayer, Davis and Schoorman (1995) suggested that trust depends partly on the trustor's propensity to trust and partly on characteristics of the trustee (specifically their perceived ability, benevolence and integrity). Trusting behaviour results from the psychological state of trust, and risk taking is the outcome. However, from their review, Dirks and Ferrin (2001) found strong evidence that trust had a direct effect only on behavioural outcomes such as organisational citizenship and individual performance together with attitudes and perceptions. For Dirks and Ferrin (2001) trust leads directly to behavioural outcomes only where the organisational motivational structure (such as the incentive system) for the outcome is weak. Where the motivational structure is strong, trust will have no discernible effect. Where the motivational structure is indeterminate, then the effect of trust will be a facilitating effect. Thus Dirks and Ferrin (2001) added complexity and dependence on the organisational context to Mayer, Davis and Schoorman's (1995) model.

To the increasingly complex model of trust being built up, Lewicki, Tomlinson and Gillespie (2006) add two additional considerations. The first is that trust does not always start from zero. Trust can exist before work begins. But also, that distrust is separate from trust, and not just a situation of low trust. This means that trust and

distrust can co-exist, for example an individual may exhibit trust of another over some issues, and distrust over others. Thus both trust and distrust exist at different levels and over different issues, vary over time, and are affected by the feedback loop of experience. To manage the emerging complexity, Fulmer and Gelfand (2012) suggest that analysis of trust should always specify “trust *at* a level of analysis and *in* a referent” (Fulmer and Gelfand, 2012, p. 1168, italics original) so that the trustee and the trustor are clear. Here then the level can be the individual, project team, organisation or network and the target of the trust must be established.

For this study of PPI in an ION, then, trust is a psychological state involving one party voluntarily giving another power to such that a risk is taken. The extent of the trust depends partly on the trustor’s propensity to trust, and partly on characteristics of the trustee. Whether the effects of trust are discernible as main effects or facilitators will depend partly on the organisational context. The starting conditions of trust and distrust vary with context, and the levels vary with time and experience. Trust by an individual, project team, organisation or network can be placed in an individual, project team, organisation, or network.

#### **2.7.10 Extent of the involvement**

Following the framework in Figure 2.10, if the functional variables are important to how PPI works, then they should affect the extent to which the public are involved. SNA can be used to produce network maps showing the extent of this involvement. If the public and the professionals are working together to deliver healthcare projects, then the links between them can be mapped to demonstrate the involvement. If the PPI programme is working effectively, then the public contributors should have become part of the network of professionals delivering project work. An SNA should result in network maps with reciprocal connections between professionals and public contributors, where information and ideas about project work flow in frequent interactions.



### 2.7.11 Value

Value can be called the ‘effects variable’ for the purposes of this thesis. One theme common to both the PPI and ION literatures was how hard collaborations are to assess. The two literatures also shared underlying assumptions. The first, the primacy of evidence-based knowledge, is accepted in this thesis as a way to convince a range of audiences. This thesis attempts to move this debate forward by showing evidence of the value of PPI that is not anecdotal, and which can thus gain easier admittance to the evidence base in health theory and practice. The second shared underlying assumption, the dominance of the professional and institutional agendas, is not accepted here. In order to challenge this dominance, the term value is used in explicit rejection of ‘impact’ and ‘effectiveness’ and the requirement to improve PPI in order to deliver better research and service delivery outcomes and thus attract funding. It follows that involvement is accepted as a right (and a responsibility) for citizens, and the reason for evidencing value is to use that evidence in an emancipatory way to assist public contributors. This evidence will also have lessons for academics, professionals and institutions, but these will be lessons in how to enhance the PPI rather than in how to obtain better research or service outcomes. Since the evidence cannot be easily dismissed as anecdotal, the lessons might prove more acceptable.

The notion of value here reflects a synthesis of the PPI and ION literatures in that it holds that PPI should have a value in terms of the corroborated effects that are traceable back to the contributions actually made by members of the public, and not to individual perceptions, nor to measuring only those effects anticipated in advance by the team and answering questions dominated by professional and institutional agendas. The value here occurs within the overall context of an NAO, within a particular PPI structure, in projects that function in a particular way, and where the extent of the involvement is understood. The centrality of the public contributors and their contributions helps to put the ‘public’ piece of public value in place. At the same time, the open search for value is assisted by the idea that it may occur at multiple levels. The effects may be on the individuals (the professionals or the public contributors), the clients (either through direct health outcomes or proxies where the projects implement evidence-based interventions), the community

(especially where the involvement is of previously marginalised groups), the organisation (at the NAO itself) or the network (the member organisations).

## **2.8 Revised research questions and propositions**

The critical realist review of the literature has changed the overarching research question to, *what is the nature of PPI in inter-organisational health networks, and how is it valued?* This change reflects the need to establish the form of the PPI and the extent to which it has successfully involved the public before evidencing its value. Changes to the detailed research questions and linked propositions follow the conceptual framework, such that there is a question and related proposition(s) for each element of the framework. The relationship between the research questions and the framework is illustrated in Figure 2.12.

1. *What is the nature of the context that inter-organisational health networks provide for PPI?*

Proposition 1.1: If the PPI programme benefits from the NAO form of a health organisation then there will be evidence of staff deploying some or all of: negotiation, boundary spanning, teaching, coaching and mentoring skills.

2. *What is the structure of PPI in inter-organisational health networks?*

Proposition 2.1: The structural variables can be used to describe the organisational intent of PPI in an inter-organisational health network.

Proposition 2.2: The structural variables do not affect the effectiveness of PPI in an inter-organisational health network.

3. *How does PPI in inter-organisational health networks function?*

Proposition 3.1: The functional variables can be used to describe how PPI in an inter-organisational health network operates.

Proposition 3.2: The functional variables affect the effectiveness of PPI in an inter-organisational health network.

4. *To what extent can public contributors be regarded as part of the inter-organisational health network?*

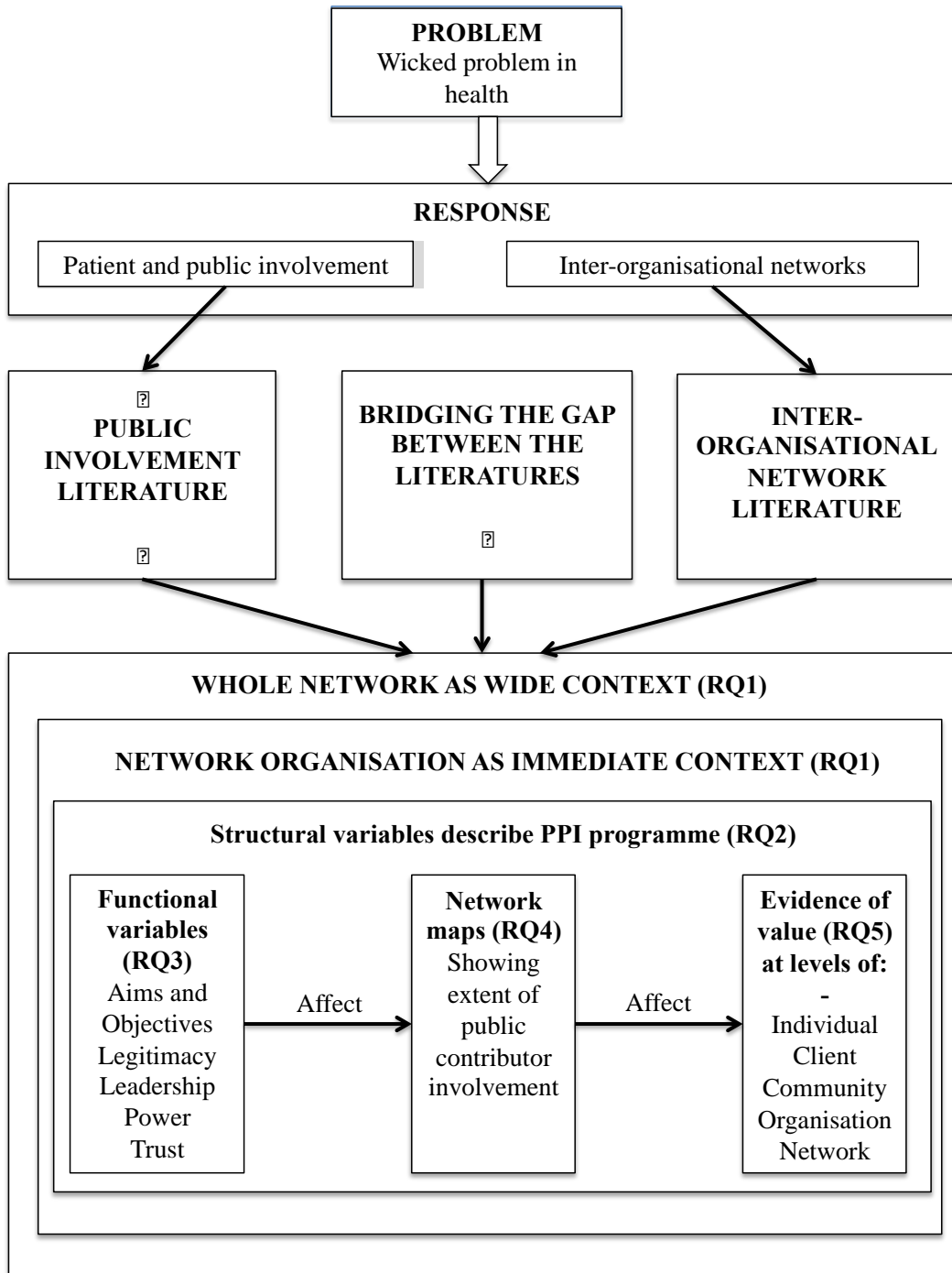
Proposition 4.1: If public contributors are part of the inter-organisational health network then there will be evidence of multiple, strong links between them and the health network professionals and among public contributors.

Proposition 4.2: The number and strength of links between public contributors and professionals in the network is a measure of the extent of the PPI.

5. *How is PPI in inter-organisational health networks valued?*

Proposition 5.1: Extensive PPI affects value creation at one or more of individual, client, community, organisation or network levels.

**Figure 2.12 The link between the framework and the questions**



## 2.9 Conclusion

In England, PPI and IONs have been parallel policy responses to wicked problems in health. They have spawned parallel literatures with little overlap. However, some common themes emerged in each. Both contained helpful typologies, indications as to what enables successful collaborations, and debates on the nature of the value from collaborations. Each literature also presents major limitations for its use in evidencing the value of PPI in an ION. The PPI literature contains little attempt to categorise context so as to allow results to be cumulated and theory to be built. The general citizen does not bring experiential knowledge, and so the PPI literature contains little account of their legitimacy or the roles they might play. Finally, the PPI literature has typically not brought a wider collaboration literature to bear on the problem of involving citizens. The ION literature, on the other hand, focused on connections between organisations, and provides little assistance for examining the interactions between organisations and individual citizens.

This chapter demonstrates that viewing networks at multiple levels and allowing that organisations are built of individuals connected in blocks permits the construction of a network of individuals and organisations. Thus PPI can be viewed as one specific form of collaboration in an ION. This critical realist review of the literature synthesises the PPI and ION literatures into a novel conceptual framework. The framework uses established typologies to categorise the context for PPI as a mandated NAO. The framework proposes that functional variables, more than structural variables, affect the extent of the public's involvement, which can be mapped using SNA. Similarly, the framework proposes that the extent of the involvement affects the value of PPI, found at multiple levels. In line with critical realist reviews, the conceptual framework now requires evaluation against the evidence. The next chapter sets out the methodological approach.

## **3 Methodology**

### **3.1 Introduction**

Yin's (2014) case study provided the methodology for this thesis evidencing the value of PPI at the AHSN, although the debate concerning whether case study is a methodology is acknowledged. This chapter first shows how critical realism underpinned the case study approach. Case study can be used with a range of ontologies, and Section 3.2 shows that Foucauldian discourse analysis was considered but rejected. Realism provides an especially good fit with case study (Yin, 2014), and critical realism was selected from the raft of possible realist approaches.

This chapter sets out the fit between Yin's (2014) definition of case study and PPI at the AHSN before presenting the five key elements of the research design. Sub-sections on each element of quality in case study show how techniques of triangulation, a chain of evidence, review by a public adviser, explanation building, theoretical propositions, a protocol and an auditable database have been used. The section on ethics describes protecting participant anonymity as a major challenge, and sets out how this was done. The sample selection is identified as variety-based, and the three major data sources as observation, documents and interviews. The final section details each step taken in the data analysis.

### **3.2 Critical realism**

Although critical realism underpinned the design and conduct of this research, a number of factors prompted consideration of Foucault's discourse analysis as an alternative. Foucault used the approach in fields of medical discourse, and PPI could be considered a branch of medical discourse with all that implies about the relative importance of scientific versus lay knowledge. Foucault illuminated theorisations about power (Foucault, 1978), and power is a key consideration in collaborations, and thus in PPI. Finally, Ferlie *et al.* (2009) found Foucauldian analysis helpful in understanding behaviour in health IONs. However, despite these arguments in favour, discourse analysis did not offer a good enough match with the research

questions. Foucault (2002) requires the identification of a field (such as PPI) so as to examine the field's discourse, and establish the rules and relations governing it. For Foucault, the questions are related to how knowledge is constituted in that field. By contrast, this thesis asks about the nature of PPI and what value it delivers. The overarching research question is about the PPI, rather than about the discourse of PPI, even while acknowledging that the discourse may have had an effect on the PPI. In addition, discourse analysis would seem to necessitate a wider scope than a single organisation, and a longer timespan than the 16-month data collection period. Finally discourse analysis did not seem to offer the best use of excellent access to contemporaneously unfolding events.

The focus of the rest of this section is to demonstrate that critical realism provided a good fit for the study of a social phenomenon, where the questions sought explanations and causes. After a brief introduction to critical realism showing where it sits in a continuum of ontologies, this section explores Bhaskar's (1975) critical realist approach to the natural sciences, and then to the social sciences (Bhaskar, 1989) with a focus on showing the ways in which critical realism has influenced this thesis. Critical realism offers the social scientist the opportunity to be a scientist without being a positivist: a scientist because the aim is the production of knowledge through rigorous thinking and study design. This rigour, and the emphasis on well-designed studies, provide a strong link to Yin's (2014) case study methodology. The attraction of critical realism lies in its attempt to synthesise important ideas from different traditions – much as this thesis attempts a synthesis between the PPI and ION literatures. Table 3.1 below reproduces a table from Rousseau, Manning and Denyer (2008, table 11.1, p. 486) locating critical realism between positivism and relativism across some key characteristics.

**Table 3.1 Alternative epistemologies**

	<b>3.2.1.1 P o s i t i v i s m</b>	<b>3.2.1.2</b>	<b>3.2.1.3 R e l a t i v i s m</b>
Reality	Objective	Objective yet human interpretations effect observed reality	Socially constructed
Application of evidence	Confirmatory. Only what is observable exists	Falsification	Critical
Data	Concrete and quantitative	Observations, judgements, and interpretations; quantitative and qualitative	Text – spoken or written
Focus	Observation as reality	Causal mechanisms identified via fallible observations	The sense people make of the social world

Table 3.1 reproduces “Alternative epistemologies in management and organisational research” (Rousseau, Manning and Denyer, 2008, table 11.1, p. 486). Used with permission from the Academy of Management.

Bhaskar (1975) called the approach transcendental realism, but it has come to be known as critical realism when applied to the social sciences (Sayer, 2000). It is helpful to understand how the approach accounts for scientific knowledge first, before considering its application to the social sciences. Bhaskar (1975) considered what the world must be like (the ontology) in order for scientific knowledge (the epistemology) to be possible. Bhaskar (1975) proposed that there is an enduring

world of things that is independent of us and our knowledge of it. Bhaskar (1975) called this world of enduring objects the intransitive dimension. For Bhaskar these objects are real, and possess structures and mechanisms that are independent of our ideas or models of them. In Bhaskar's understanding, this enduring world of things can be regarded as an open system where multiple potentially causal mechanisms exist and interact to produce, or not, certain phenomena. The world is stratified into different levels. Science understands the world in the opposite direction to which it is built up, that is from the least fundamental level to the most (Bhaskar, 1975).

Science is the rigorous work of producing knowledge (Bhaskar, 1975). It is a social activity where transitive (or "fallible", Sayer, 2000, no page) knowledge progresses by building on the knowledge developed by previous generations. Scientists take imaginative leaps by building theories and models, and then conducting experiments to test these. A real generative mechanism (or cause) may not lead to any actual event, or any event that is perceived by scientists. Perhaps the generative mechanism has been counteracted by another mechanism also operating in the open system. A real generative mechanism may realise its tendencies and lead to an actual event that is nonetheless not detected by scientists. Finally, a real generative mechanism may operate and actually lead to an effect that is empirically perceived by scientists (Bhaskar, 1975). For most of the time, the link between cause and perceivable effect does not operate. This means that predictions about the effects of generative mechanisms can only be made in closed systems, and falsifications likewise. In this view, scientific laws express the tendencies or powers of things that may not be realised in open systems because things may be subject to multiple tendencies or laws (Bhaskar, 1975). Laws also express the conditions under which events occur, but do not determine whether they actually happen or not.

Some critics have argued that Bhaskar's (1989) extension of critical realism into the social sciences fails. For example, Kemp (2005) found that whereas fundamental physics had an accepted method for building knowledge, supported by wide consensus, social science did not. Thus Bhaskar's (1989) transcendental reasoning, which suggested that social structures can be viewed as real and intransitive, did not move successfully to social research. According to Sayer (2000), other critics have suggested that in fact the social world is constructed by our knowledge of it, thus the



researcher and the researched cannot be separated. But critical realists have argued that social phenomena exist regardless of a researcher's presence, that most theories are influential primarily in academia but not outside it, and that social practice and theoretical concepts are not identical (Sayer, 2000). There are differences between the social world and the natural world, though. For example, social structures exist only in open systems (Bhaskar, 1989). While other realists have argued that partial closure is possible in the social sciences (for example, Pawson, 2013), critical realists assert that the social system cannot be closed. This is not just because there are too many variables to control, but because "they are necessarily peopled" (Archer, 1998, p. 190). If a system cannot be closed, then theory cannot be tested by triggering a cause and perceiving the effect (Bhaskar, 1989). Thus critical realists are unable to use predictions as a way to choose between competing theories. Instead, Bhaskar (1989) suggested that theories are judged based on their explanatory power, while providing no detail on how to do this. Judging between the explanatory power of rival theories has been described as "one of the most difficult questions social researchers ... have to face" (Sayer, 2000, no page). Although Pawson (2013) has accused critical realists of being uninterested in using evidence to dispute theory, critical realists certainly write about the importance of justifying theory with empirical data (Porter, 2015). In terms of actually making the judgements, two suggestions help. The first is that the value of an explanation lies in sorting out what can be the case from what must be the case (Sayer, 2000). The second is the "practical adequacy" (Sayer, 2000, no page) of the theory. These two approaches to the explanatory value of a theory are used in the discussion chapter (Chapter 5) to evaluate the conceptual framework developed in the literature review (Chapter 2).

Experiments and system closures give scientists "practical access" (Bhaskar, 1989 p. 47) to their subjects. Social scientists get this practical access from being a part of what is studied. Thus Bhaskar (1989) saw the fact that social scientists are internal to their subject as an advantage even while acknowledging that the act of study may cause changes in the study subject. Law-like statements are still possible, but they are restricted to defined parts of the system, operating at a certain time, and describing tendencies that may never have an effect due to the presence of multiple potential generative mechanisms. Bhaskar (1989) finds that there is no objectivity in

social science because knowledge is socially produced. To be precise definitions must use words that are value-laden and hence meaningful. This emphasis on meaning accounts for the space devoted in this thesis to building definitions from the existing literature (see Chapter 2, Section 2.3). Shared definitions are the first step in a process of integration and knowledge accumulation (Rousseau *et al.*, 2008).

The main area of study should not be behaviour, but relations (Bhaskar, 1989). Given this, critical realism seemed especially apt for this study where a real social phenomenon (PPI) was explored partly using SNA, which explicitly focuses on the nature and extent of relations between actors. Bhaskar (1989) described the dual nature of society and intentional human activity: society is a pre-existing condition for human activity, and also the result of it. Society is produced by conscious human activity, and also reproduced by it. Human activity is intentional not only because it initiates deliberate change, but also monitors it, monitors the monitoring and can provide a commentary on it. Thus to the empiricist's observation data, critical realist studies like this one can add interview data explicitly to access the participants' own view of events (Sayer, 2000). Intentional human activity is caused by a reason. The reason can be generated internally by the individual or supplied by someone or something external. Reasons generate actions only if they are exercised, and their exercise may depend on conditions or countervailing reasons. Human being thus possess "potentialities" (Sayer, 2000, no page) to change or influence events. In this thesis, for example, the potentiality of public contributors to play a range of roles is examined in detail in Chapters 4 and 5.

### **3.3 Case study methodology**

Case study provides a good fit with critical realist ontology. Both case study and critical realism explicitly account for the context surrounding a social phenomenon, both are permissive in terms of the type of data that can be used (both quantitative and qualitative), the sources of data (observation, interviews, documents), and both emphasise finding explanations and causes through rigorous research design. However, what needs to be explored further is whether case study is a methodology,

that is, an overall framework guiding both what is studied and how it is studied (Yin, 2014) rather than just one method (or technique).

Case study is a widely used term, but some authors mean something quite different to Yin (2014). For example, in the constructivist paradigm, Lincoln and Guba (1985) state, “the case study is primarily an interpretative instrument for idiographic construal of what was found there” (Lincoln and Guba, 1985, p. 189) and ideal for presenting the “thick description” (Lincoln and Guba, 1985, p. 214) that promotes understanding of the specific study subject. For Yin (2014) this would be the case report, not the case study itself. Even well known writers on case study do not agree that it is a methodology. Instead, case study is seen as a technique to select and scope the boundaries of a study subject (Flyvbjerg, 2011), like a person or a programme (Stake, 1995).

Yin’s (2014) case study has been adopted as a methodology here for two key reasons. First, Miles, Huberman and Saldana (2014) recommended that early career researchers use a “tight” (or thoroughly shaped design) rather than a “loose” (or emergent) one (Miles, Huberman and Saldana, 2014, p. 16). Second, consistent with critical realism, the aim in this thesis is to identify causal explanations. Avoidance of causal misattribution requires a rigorous research design (Sayer, 2000), which Yin’s (2014) case study methodology should help to provide. However, adopting Yin’s (2014) methodology has not meant blindly following a checklist, which Barbour (2001) warns is not a route to quality research. After all, “good research is not so much about good methods as it is about good thinking” (Stake, 1995, p. 19). Rather, Yin’s (2014) methodology has been used to provide a guiding framework to ensure that the research design is appropriate to the research question and that it strives to deliver against the key measures of quality in qualitative research.

### **3.4 Case study definition**

This section shows how PPI at the AHSN conformed to Yin’s (2014) two-part definition of case study research. Here a case study encompasses both what is studied and how it is studied: -

“1. A case study is an empirical enquiry that

- investigates a contemporary phenomenon (the ‘case’) in-depth and within its real-world context, especially when
- the boundaries between phenomenon and context may not be clearly evident” (Yin, 2014, p. 16)

While case studies could be historical as well as contemporary (Swanborn, 2010), they are more likely to be contemporary accounts (Eisenhardt and Graebner, 2007). This thesis followed Yin (2014) and examined only contemporary instances of PPI at the AHSN, so that observations, as well as interviews and documents, could be used as a data source. This multiplicity of data sources then permitted corroboration between sources. The importance of the network context to PPI at the AHSN formed an explicit part of this study, as shown in the conceptual framework developed in the literature review (see Chapter 2, Figure 2.10). The aim was to demonstrate which elements of the context were “constitutive” in PPI, rather than just “passive” (Sayer, 2000, no page).

The second part of Yin’s (2014) definition says: -

“2. A case study inquiry

- copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result
- relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result
- benefits from the prior development of theoretical propositions to guide data collection and analysis” (Yin, 2014, p. 17).

The number of variables in the study of PPI at the AHSN was high because the enquiry was in-depth, conducted over 16 months and included data collected about the context. As per Yin’s (2014) definition, the case study provided few data points. This situation would not support statistical analysis (which requires multiple data points for each variable) hence the requirement for multiple data sources

(observation, interviews and documents here) and the anterior development of theoretical propositions.

While Yin's (2014) definition of case study emphasises the benefit of theoretical propositions, the role of theory is a contested area in qualitative research.

Naturalism, for example, rejects the idea that the purpose of social science is to build theory (Lincoln and Guba, 1985). Instead, the job is to understand the specific case in its context. Generalisations, or law-like statements that encompass all cases and all contexts, are not possible in a paradigm characterised by multiple, constructed realities. Grounded theory, on the other hand, does develop theory, but does not approach the data with pre-formed theory (Glaser and Strauss, 1967). Consequently Eisenhardt (1989) suggested not using existing theories or propositions in case study. Variables of interest should be identified, but the relationships between them not developed. Both the research questions and the variables are then held as tentative lines of enquiry. Each could change and neither is guaranteed a place in the final theory if they do not also emerge from the data. In this way, the aim is to "develop theory inductively" (Eisenhardt and Graebner, 2007, p. 25).

Critical realism, though, supports the aim of generalising to theory and approaching data with pre-formed theory. In critical realism theory is developed through sorting out necessary relations from contingent ones. Necessary relations are generalisable to other contexts. Contingent ones are specific to the context studied (Sayer, 2000). And while data collection and analysis might be "theory-laden", they are not "theory determined" (Sayer, 2000, no page). Using propositions therefore presented a good fit between critical realism and Yin's (2014) case study methodology. In this thesis review and synthesis of the existing literatures in PPI and IONs led to the development of a conceptual framework containing the variables that were the focus for the research (Miles, Huberman and Saldana, 2014). In this way, the conceptual framework enabled a movement from the profusion of variables characteristic in case study to the few chosen for investigation. The posited relationships between the variables in the conceptual framework informed the research questions and the theoretical propositions and provided a logical link to the data collection and analysis.

### **3.5 Case study design**

According to Yin (2014) there are five key components of research design: the questions, the propositions, the units of analysis, the way the data is linked to the propositions, and the way the findings have been interpreted. This section presents a discussion of research question development before turning to the remaining four components. Throughout, the case, PPI at the AHSN, is seen as having been set by the wider research project.

#### **3.5.1 Research questions and propositions**

The research objectives should be framed as questions at the start (Yin, 2014). The initial research questions for this thesis can be found in Chapter 1, Section 1.6. This approach offered focus right from the beginning, although the questions did change. Different approaches expect different degrees of change to the research questions. For Eisenhardt (1989), research questions are tentative and may shift during the research. For Stake (1995), the questions naturally evolve. In this study the literature review sharpened the questions (Yin, 2014) through building the conceptual framework, which is a specific technique suggested by Miles, Huberman and Saldana (2014). The final research questions can be found in Chapter 2, Section 2.8. Critical realism directs researchers to ask questions about generative mechanisms (Rousseau *et al.*, 2008). Generative mechanisms are found, not at the superficial surface, but deep in the structure of things. Case study methodology helps to examine generative mechanisms by asking ‘how’ and ‘why’ questions (Yin, 2014).

#### **3.5.2 Units of analysis**

The wider research project dictated both the single case nature of this research design, and the selection of that case: PPI at the AHSN. Both of these prescriptions were potential design weaknesses. A single case design is generally seen as less robust than a multiple case design (Yin, 2014) because it does not allow replication (literal replication where the results are repeated, or theoretical replication where the results are different but explained). Accepted rationales for single case research designs include cases that are “critical, unusual, common, revelatory, or

longitudinal” (Yin, 2014, p. 51). An unusual case can be either an extremely good or an extremely bad example (Flyvberg, 2011).

Two justifications for a single case design applied here, even though neither determined the case selection. The AHSN could lay claim to being an extremely good example of PPI. The chair of INVOLVE called the region an “exemplar” (Denegri, 2015) in PPI. This accolade was aimed at the collaborative partnership in which the AHSN was one of four partners and which had drawn up a shared PPI strategy (see Chapter 1, Section 1.5). Denegri added that some other regions had yet to move from first base. Also, the AHSN had applied best practice guidelines to their PPI programme (UWE, 2011). For example, public contributors were selected using a transparent process, had a written job description, were paid, were deployed in pairs, had representation on the board and were a standing part of the AHSN’s work. In this sense, PPI at the AHSN could be seen as an extremely good example of involvement and worthy of single case study. The longitudinal nature of the case provided the other justification. Data collection took place over 16 months, allowing changes over time to be captured.

Single case study design incorporates two variants, “holistic” and “embedded” (Yin, 2014, p. 53). Each design creates strengths and weaknesses. For this research, an embedded design offered the potential to understand the operational detail of PPI, rather than studying the global intent of the PPI programme in an abstract way (Yin, 2014). Here the embedded design meant selecting “embedded units” (Yin, 2014, p. 55) or AHSN projects actually involving members of the public. The danger of an embedded design is the risk of only investigating at the level of the projects, and failing to realise the intent to examine the case unit, or PPI at the AHSN (Yin, 2014). This research investigated at the case level by collecting data from AHSN-wide PPI documents, and by including the AHSN PPI manager as an interviewee.

In deciding the number of embedded units, the scope of doctoral research weighed against a desire to understand PPI in a range of circumstances. Examining three AHSN projects, each deploying PPI, offered the most appropriate balance of workload with breadth. Purposive, “maximum variation” sampling (Miles, Huberman and Saldana, 2014, p. 32) to capture the broadest possible operative

range of PPI at the AHSN was set against the need to select projects that were operational during the research period and avoid projects chosen by other research strands. In the event, only one project from Department 2 (see Figure 1.1) was a candidate for both this and another research strand. This project was assigned to the other research strand as Department 2 was running a second project featuring PPI, but no other projects relevant to diffusion innovation.

The PPI Manager at the AHSN assisted the project selection during several meetings in the first 18 months of this doctoral research. The projects selected varied across the following axes: -

- projects from three different AHSN departments
- projects of different lengths
- projects with different structures
- projects at different stages of maturity

The three projects, codenamed P1, P2 and P3, are mapped in Table 3.2 against these axes of possible variation.

**Table 3.2 The three embedded units**

	<b>AHSN department</b>	<b>Project length</b>	<b>Maturity</b>
Project 1 (P1)	Department 1	Four months	Data collected from start to planned finish.
Project 2 (P2)	Department 2	One year	Data collected from the start to the unexpected finish.
Project 3 (P3)	Department 3	Indefinite	Data collected from an already established, on-going project.

The projects provided variety in three additional ways. First, all the projects included the public contributors in their steering groups, but the nature of the steering group activity differed substantially between P1 on one hand and P2 and P3 on the other. In P1 the steering group formed an operational group responsible for delivering the project. The major decisions on, for example, project aims and budget, were taken by a project board on which the public contributors did not sit. By contrast, P2 and P3 did not have a project boards. The P2 steering group made the major decisions, whereas the AHSN staff undertook the operational work for delivering the outcomes with AHSN member organisations. Similarly the P3



steering group made the major decisions, but P3 formed sub-projects to deliver outcomes in concert with AHSN members. The public contributors could attend P3 sub-projects if they had an interest in the work. One P3 public contributor did attend P3 sub-project meetings, and these formed part of the data collection for this study.

The second additional variation between the projects concerned the presence of AHSN member organisations. In P1, member organisations were invited to the project steering groups, but not expected to attend. And in fact, no AHSN member organisations did attend any P1 steering group meetings. AHSN staff updated member organisations offline with emails and telephone calls. Both P2 and P3, however, included AHSN member organisations in the steering groups. While P3 was well attended and established, P2 struggled to attract attendance from its members, causing the group to be terminated after just three quarterly meetings. The third additional variation concerned the presence of other types of public. P1 involved public contributors in a project aimed at inviting ideas and input from the general public. The general public attended meetings to be informed about the project, and to make suggestions based on their own experience (defined as engagement in this thesis). In this way, P1 included public contributors who were involved in the project ‘with’ professionals, and members of the general public who were engaged with the project which was done ‘to’, ‘about’ and ‘for’ them (INVOLVE, 2015). So P1 operated with two different types of public.

### **3.5.3 Linking data to propositions**

This aspect of the research design anticipated the later data analysis, ensuring that, when analysed, the data collected would allow examination of the propositions (Yin, 2014). In this thesis the conceptual framework informed the propositions which hypothesised the relationships between variables. “Explanation building” (Yin, 2014, p. 149), where the propositions are compared to the data and then revised, provided the major analytic strategy. In this research, the conceptual framework helped to show what data would need to be collected. For example, the contextual impact of an NAO on PPI required data collection about network-based soft skills. Examining the structure of PPI required data collection covering all the structural variables. Examining the functioning of PPI required data about the

functional variables. Understanding the number and nature of links between public contributors and professionals meant collecting data about these links. Finally, evidencing the value of PPI meant both observing the effects of PPI and asking participants interview questions about the difference public involvement had made.

#### **3.5.4 Criteria for interpreting findings**

The intent behind considering how the findings will be interpreted in the research design is to strengthen the credibility of the research (Yin, 2014). In case study, Yin recommended the explicit consideration of rival theories or explanations. For this thesis, the consideration of rival explanations meant collecting all the data relating to the variables in the conceptual framework, whether that data supported or contested the hypothesised relationships. Review of an interview transcript by the doctoral candidate's academic supervisors checked for variables present in the data, but not in the conceptual framework (see Section 3.9 for further detail). The analysis and subsequent write up in the findings chapter (Chapter 4) included all the data, whether it supported the hypothesised explanation or not.

### **3.6 Quality in the case study design**

Case study methodology sets out to build quality into social research through rigorous design. For each quality criterion, case study methodology identifies appropriate tactics (Yin, 2014). However, Yin's criteria and the tactics are both contested areas in the literature. For some critics the tests below adopt the language and approach of a positivist paradigm rather than being appropriate to qualitative research (Lincoln and Guba, 1985). The tests have been adopted in this thesis because of the critical realist emphasis on explanations, and the subsequent need to adopt a systematic approach in order to avoid causal misattributions. The following sub-sections detail the quality criteria, the tactics Yin identifies, summaries of the debate in the literature, and descriptions of the approaches adopted in this thesis and why.

### 3.6.1 Construct validity

Construct validity concerns the link between the concepts being studied and the way they are measured in the research. Eisenhardt (1989) used power as an example of a construct. Power relationships cannot be physically measured using an instrument. In this thesis, power is associated, for example, with influence over decisions and meeting agendas (see Table 3.5). This operationalisation then needs to be measured which means deciding what success or lack of success getting items on the agenda looks like. The tactics recommended are: multiple sources of evidence to triangulate; a chain of evidence; and report review by informants (Yin, 2014). These tactics are explored in turn in the paragraphs below.

Critics doubt whether triangulation is as useful as Yin (2014) indicated. Data source triangulation is seen as time-consuming and arduous, and only worth using in critical areas (Stake, 1995). Evidence from multiple data sources tends to be parallel rather than convergent and leads to comprehensiveness rather than corroboration (Barbour, 2001). The use of triangulation may (falsely) suggest, “increasing fidelity [to] a single, valid representation of the social world” (Coffey and Atkinson, 1996, p. 15).

There are two issues to unpick here: the usefulness of triangulation to this thesis generally, and the usefulness of triangulation as a specific tactic to improve construct validity. For this thesis, based on a single case study and with no possibility of replication, the strongest evidence was held to be that which had been corroborated, thus this thesis actively pursued triangulation as one way to mitigate the inherent limitations of the study design. Similarly, in order to be transparent, the extent of the corroboration is noted, to allow the reader themselves to participate in judging the creative process of drawing meaning from the findings. In line with a commitment to present all the data, uncorroborated data and dissenting voices are always depicted, but the use uncorroborated data are put to depends partly on the nature of the question being considered. In a famous example, the hypothesis that all swans are white can be falsified by a single data point (the black swan). A research question aimed at exploring how individuals construct their own identities might similarly rely on uncorroborated accounts. In a further illustration, individual

outliers might cumulate (in the language of Pawson and Tilley, 1997) to provide a strong body of evidence. On the other hand, a research question aimed at exploring an organisational approach might require accounts from individuals, plus corroborating documentation and observation data. Consequently, the use of uncorroborated data in this thesis depends on the particular research question or proposition. While triangulation is viewed in this thesis as a useful technique in some circumstances, it does not appear to offer a test of the validity of a construct. Multiple sources of evidence might corroborate that public contributors added items to meeting agendas, but this does not test whether this is a good way to operationalise ideas of power. Thus triangulation has some value, but not as a tactic for improving construct validity.

Similarly a secure chain of evidence might seem to ensure that claims are based soundly on data, and thus to improve the “reliability” (Yin, 2014, p. 127) rather than the construct validity. Consequently, a secure chain of evidence is adopted in this thesis because it represents good research practice, rather than because it offers construct validity. This thesis can trace the findings on any concept to the specific source, to the propositions, to the research questions and back again. The tactic of report review, on the other hand, does seem to affect construct validity because participants can say whether the constructs used resonate with them. To obtain review and feedback within the constraints of a doctoral timetable, the public adviser reviewed the constructs within the conceptual framework and offered feedback on their resonance to the experience of public contribution.

### **3.6.2 Internal validity**

Internal validity concerns whether a causal relationship between two variables really exists (Yin, 2014). The recommended tactics are all analytic strategies: pattern matching, explanation building, addressing rival explanations, and logic modelling which lays events out in time sequence to ensure that posited causes always precede effects (Yin, 2014). Lincoln and Guba (1985) criticise the notion of internal validity as belonging to a positivist paradigm where there is simple cause and effect and one single truth. In place of internal validity, constructivists use “truth value” (Lincoln and Guba, 1985, p. 294) which rests on whether research is credible, that is, whether

it shows that multiple constructions of reality have been satisfactorily represented. However, constructivism appears to give equal weight to all the available constructions of reality. Critical realism, by contrast, may admit more than one construction of reality, but can rule out constructions that are not supported by the evidence (Sayer, 2000). For example, PPI may be constructed as a way to improve participatory democracy or as mere tokenism, but cannot be constructed as jury service. The use of internal validity does not signal positivism because the cause and effect here is “generative” rather than “successive” (Pawson and Tilley, 1997, p. 32) such that a trigger may change something inside a subject so that the outcome requires both the trigger and the internal change.

This doctoral research used propositions to hypothesise the relationships between variables. The findings were then compared with the propositions. The propositions were revised when the evidence did not support the explanations posited in the propositions. Collection, analysis and presentation of all the data (supporting and contesting) ensured consideration of rival explanations. Logic modelling, in diagram form, during the analysis stage ensured that causes always preceded outcomes in any claims for a causal relationship.

### **3.6.3 External validity**

External validity concerns the extent to which research findings can be applied to situations outside the immediate study subject. According to Flyvbjerg (2011), one of the common misunderstandings about case study research was that it is not possible to generalise on the basis of a single case. However, not everyone agrees that generalisability is a priority, “our first obligation is to understand this one case” (Stake, 1995, p. 4). Still others see the “applicability” of research in other contexts as the responsibility of the reader (Lincoln and Guba, 1985, p. 296) rather than the original researcher. For Yin (2014) and for those working on case study in a realist paradigm, including critical realism, single case studies can be generalised to theory (rather than to populations). Thus “we move from one case to another not because *they* are descriptively similar but because *we* have ideas that can encompass them both” (Pawson and Tilley, 1997, p. 119, italics original). Therefore, this study’s

claims to external validity are based on using existing concepts of collaboration to explore a particular kind of collaboration, PPI, in a particular case, the AHSN.

#### **3.6.4 Reliability**

Reliability concerns demonstrating that a study could be repeated with the same results (Yin, 2014). For a case study to be repeatable, the case must have been documented thoroughly. Yin recommends behaving as though an auditor was standing over the research, and using both a case study protocol and a database (Yin, 2014). While critics disagree whether any study in a changing social world can ever be repeated, the prescription (an audit, or at least an auditable study) remains the same (Lincoln and Guba, 1958). Thus this thesis aims to be auditable from the start, keeping a case protocol (see Appendix 5) that focuses on demonstrating the link between the research questions and the data sources (for both chain of evidence and reliability purposes).

In this doctorate the software application NVivo 10 (supplied by QSR International) held the complete case database. All documents and files in the database could be searched easily (Yin, 2014) using the consistent file name convention of 'date\_project\_participant and data source type'. Different folder types, called 'internals' in NVivo, kept raw data sources separate from researcher commentaries, held as 'memos' (Yin, 2014) in order to maintain an auditable database.

### **3.7 Ethics**

Research into human subjects requires an ethical approach. The first key area of consideration was to establish whether the participants were from vulnerable groups (such as children, adults who are unable to consent for themselves, or adults who are in emergency or highly stressful situations). Review showed that no vulnerable groups participated in the research. In addition, none of the adult participants had any form of dependent relationship with the researcher. The next key consideration was making sure no groups were unfairly excluded. PPI at the AHSN affected two key groups: professionals and public contributors. This research valued both perspectives and included participants from each group.

In order to obtain informed consent, each participant received an information sheet and consent form appropriate to the project they worked on and their role (as a professional or a public contributor). The public adviser to this doctorate reviewed and approved the written forms. In advance of data collection activities, the consent forms were explained verbally, distributed, signed by both the participant and the researcher, and then one copy collected back to be stored in a hard copy file. The consent forms explained that participants could withdraw with the effect that interview data would not be used, and no more observation data would be collected. Representative copies of the information sheets and consent forms appear in Appendix 6.

The most difficult ethical issue for this doctorate was that of effectively protecting participant anonymity in a small organisation with a relatively short history. A number of steps were taken to provide anonymity. The identity of each project and participant has been disguised using a code. Further, ‘they’ and ‘their’ have been substituted for gendered pronouns. In order to avoid possible harm through participant identification, the following approaches were developed: at the start of each interview the researcher reminded each participant of the subject and nature of the study (the consent form having usually been signed some time before, at the start of the observations), reiterated their right to withdraw, and explained that they would be able to review a draft of the findings chapter to check their anonymity had been protected (see case protocol, Appendix 5). On review of the findings chapter, one participant advised that further abstraction in one of the tables would be helpful. This change was incorporated into the final thesis. None of the other participants raised any concerns over the protection of their anonymity.

That there are only 15 AHSNs nationally presented a further issue with anonymity. In order to protect the identity of the case, references to the organisation’s website have been adjusted. These materials are referenced as ‘[AHSN] (year) [Academic Health Science Network]. Available from [AHSN website]. [Accessed day month year]’ and cited as ‘[AHSN] (year).’ Materials from the PPI partnership of which the AHSN was a part have been treated in the same way using [PPI Partnership]. The doctoral supervisors have seen and verified the hard copy list containing the full references.

Ethics approval for this study was obtained from the Health and Applied Sciences faculty ethics committee of the University of the West of England on 28<sup>th</sup> April 2015, reference HAS/15/04/145 (see Appendix 7). The approval contained two conditions, one aimed at protecting lone working by the researcher and the other containing suggested changes to the information sheets. In order to demonstrate compliance with the ethics committee's conditions and with all the commitments made in the application, the researcher set up a tracking document, included here in Appendix 8.

### **3.8 Sources of evidence**

Multiple sources of evidence allow the opportunity for triangulation. The more the evidence corroborates, the stronger the conclusions that can be drawn. Neither archival records nor physical artefacts seemed relevant to a PPI study. The outsider status of the researcher, being neither a public contributor nor a health sector professional, meant there was no participant observer role. Hence, out of the six major sources of data (Yin, 2014), this study chose three: documents, non-participant observation and interviews (which included SNA).

#### **3.8.1 Documents**

All the projects in this study used email extensively as a communication tool, to distribute agendas, meeting minutes, meeting papers, and updates. Emails communicated between AHSN staff members, between the AHSN and member organisations, and between the AHSN and the public contributors. Emails thus presented a rich source for document review. Email data collection took the form of asking to be included on the email distribution list for each project. In addition to emails, all the three projects produced project management documents of some sort. In addition, P1 produced marketing materials aimed at the public. Comparison of the draft materials with the final printed posters and leaflets showed where changes had been made in response to public contributor comments.



### 3.8.2 Observation

Direct observation offered the opportunity to watch public involvement in action in the work of the three projects at the AHSN. It took advantage of the contemporary nature of the project. The observations preceded the participant interviews, and assisted in structuring them. When interviewees described their own behaviour or approach they could be asked if there were examples from the observed meetings. Observations took place when feasible at project meetings held during the data collection period, and at any additional events, workshops or sub-groups where members of the project team and the public contributors planned to attend. The timetables of the projects themselves thus largely determined the observation schedule.

P1 held weekly teleconferences over a few months. P2 and P3 held quarterly steering meetings. P3 also held sub-project meetings, attended by one public contributor (and the researcher). The number of observations for each project looked as follows: -

- P1 – 18 separate observations of meetings, teleconferences, and workshops
- P2 – 3 separate observations of steering group meetings
- P3 – 6 separate observations of steering group meetings and sub-project meetings

As well as audio recordings, the researcher took contemporaneous notes that were later transferred into the project database. In the case of face-to-face meetings the notes captured important non-verbal events, such as when the chair of a meeting made eye contact with the public contributors in order to allow them to interject. At the teleconferences, the notes captured non-spoken incidents such as the low audio quality of the calls. While all of the audio recordings are contained in the database, only relevant excerpts were transcribed and used for analysis. The tests for relevance attempted to capture both the presence and the notable absence of public contribution and were as follows: -

- Public contributors attended or should have attended
- Public contributors contributed or should have contributed
- Public contributors or contribution were mentioned

- Public contribution should have been sought

These tests were set out in a memo on the project database and consistently applied in choosing which segments of audio to transcribe.

### **3.8.3 Interviews**

The final data collection method was interviews. SNA questions were included in the interview questions (see the interview question guide in Appendix 5) and are detailed separately in Sub-section 3.8.4. The interviews were “guided conversations” (Yin, 2014, p. 110) rather than a closed list of survey questions. Yin describes the problems with interview evidence as being “bias, poor recall, and poor or inaccurate articulation” (Yin, 2014, p. 113). Eisenhardt and Graebner (2007) suggested that bias can be reduced through having many informed respondents who have different perspectives, using observation and longitudinal data collection. This thesis applied all three techniques. Public contributors and professionals provided different perspectives. The professionals were from different levels in the hierarchy, functions, and organisations. The 24 interviews, conducted between June 2015 and September 2016, all took place at a location of the interviewee’s choosing. With one exception, the interviews were in person and scheduled to take an hour. One interview was conducted by telephone and lasted only half an hour, due to the participant’s availability. All the interviews were recorded and subsequently transcribed on a verbatim basis.

### **3.8.4 SNA**

The intent of the SNA was to answer the fourth research question, *to what extent could public contributors be regarded as part of the network?* There was no expectation that this network would have remained stable over time, indeed the intent was to discover the connections formed around a particular piece of work. Some studies of small networks have used observation to map networks (Marsden, 2005). But here the intent of the SNA was to capture connections that occurred outside the formal project meetings. Some studies use surveys as a form of data collection, but a survey involving busy NHS professionals risks a low response rate and the chance that key connections are excluded from the resulting maps (Conway,

2014). Consequently, SNA questions formed one part of the interviews conducted with AHSN project team members, including the public contributors.

The SNA set out to map the links between individuals, some of whom were grouped together because they were staff at the same organisation. As “the search for an exhaustive network is illusory” (Charbonneau and Bidart, 2011, p. 269) the SNA set the boundaries for the network as the project. Thus the inclusion criteria for the individuals surveyed was their membership of the project team (Conway and Steward, 1998). A name generator is “a tool that uses a question or a series of questions to produce lists containing the names of persons forming an individual’s network” (Bidart and Charbonneau, 2011, p. 269). Typically names are generated by asking individuals to self-report who their contacts are (Marsden, 1990). Thus all the individuals in the AHSN project teams were asked two name-generating questions, one to capture the formal hierarchy (or responsibility for PPI in the case of public contributors) and the other to capture their links during the project (following the format suggested by Merluzzi and Burt, 2013).

The SNA asked further questions, name interpreters, about each of the names generated, also known as alters. The name interpreters captured two categories of information: the characteristics of the link, and the intensity of the link (Marsden, 1990). From the literature, respondents seem able to accurately describe their alters’ observable characteristics, but not their attitudes (Marsden, 1990), so that although weak relationships may be omitted, strong connections formed by frequent, meaningful work discussions between alters should have been accurately reported.

### **3.8.5 Sampling**

Sample selection for this study was “purposive” (Miles, Huberman and Saldana, 2014, p. 31), or the result of deliberate selection, rather than random. It aimed for “maximum variation sampling” (Miles, Huberman and Saldana, 2015, p. 32) for both the projects (as shown in Sub-section 3.5.2) and the participants from those projects. The projects, their participants, the roles they played, and the associated data sources are shown in Table 3.3 below.

**Table 3.3 Research participants and data sources**

<b>P1, P2, P3</b>	<b>Participant code</b>	<b>Role</b>	<b>Organisatio- n, code</b>	<b>Docu- ments</b>	<b>Observ -ation</b>	<b>Interview type</b>
All	AH14	PPI manager	AHSN	Yes	Yes	In person
P1	PC11	Public contributor	None	Yes	Yes	In person
P1	PC12	Public contributor	None	Yes	Yes	In Person
P1	AH11	Business development adviser	AHSN	Yes	Yes	In person
P1	AH12	Enterprise engagement co-ordinator	AHSN	Yes	Yes	In person
P1	AH13	Business development Manager	AHSN	Yes	Yes	In person
P1	SE11	Senior product designer	Charity, code SE.	Yes	Yes	In person
P1	SE12	Industrial designer	Charity, code SE	Yes	Yes	In person
P1	SE13	Chief executive	Charity, code SE	Yes	Yes	In person
P1	CO11	Account manager	Firm, code CO	Yes	Yes	In person
P2	PC21	Public contributor	None	Yes	Yes	No
P2	PC22	Public contributor	None	Yes	Yes	In person
P2	AH21	Programme manager	AHSN	Yes	Yes	In person
P2	AH22	Director (part of the week in a clinical role)	AHSN	Yes	Yes	In person
P2	AH23	Lead	AHSN	Yes	Yes	In person
P2	AH24	Project support officer	AHSN	Yes	Yes	In person
P2 & P3	NH21	Deputy director	Local Clinical Commissioning Group (CCG), code NH	Yes	Yes	In person
P2	NH22	Chief executive, chair of P2 and AHSN board member	Local hospital trust, code NH	Yes	Yes	By telephone

<b>P1, P2, P3</b>	<b>Participant code</b>	<b>Role</b>	<b>Organisatio- n, code</b>	<b>Docu- ments</b>	<b>Observ- -ation</b>	<b>Interview type</b>
P3	PC31	Public contributor	None	Yes	Yes	In person
P3	PC32	Public contributor	None	Yes	Yes	In person
P3	AH31	Lead	AHSN	Yes	Yes	In person
P3	AH32	Programme manager	AHSN	Yes	Yes	In person
P3	AH33	Director (part of the week in a clinical network)	AHSN	Yes	Yes	In person
P3	NH31	Chief executive, chair of P3 and AHSN board member	Local hospital, code NH	Yes	Yes	In person
P3	NH32	GP (part of the week AHSN clinical lead)	Local GP surgery, code NH	Yes	Yes	In person

As there were only six public contributors in total (two in each project), maximum variation sampling meant including all six public contributors from the three projects. However, only five public contributors were interviewed. PC21 signed the project consent forms, did not withdraw consent, was observed in the first P2 meeting, but did not attend any more P2 meetings. Neither did PC21 respond to the researcher's invitation to be interviewed.

For the professionals, maximum variation sampling meant capturing views from different levels of the hierarchy within the AHSN, from different organisations, and from those with different roles and responsibilities. The approach varied depending on the size of the project. P1 was a small project team of just nine people, so all the project team members were interviewed. As well as the public contributors this team consisted of professionals from three different organisations, and from different levels in their respective organisational hierarchies.

P2 was a much bigger team, and so interviewing everyone was beyond the scope of a doctoral thesis. In order to allow triangulation, interviewees were sought according to how many of the researcher-observed meetings they had attended.

However, there were only ever three quarterly P2 meetings. Just five people attended all three meetings including the public contributor, PC22, and four AHSN professionals. These four were from different levels of the hierarchy and all four were interviewed. No other professionals attended all three meetings. Only two other professionals attended two out of the three meetings in person. These two were from different organisations. One of these, NH21, was also a member of the P3 project team and their ability to compare the two projects seemed beneficial. The other professional, NH22, was the chair.

P3 was a still larger team. Again interviewees were sought on the basis that they had attended the meetings observed by the researcher and in order to allow triangulation between data sources. Member organisations often sent deputies, if someone could not attend. Four regular attendees from different levels of the AHSN were selected. The chair, NH31, from a local hospital trust attended all the observed P3 steering group meetings. The final participant, another frequent attendee, worked as a clinician for part of the week, and then represented primary care at the AHSN one day per week. Overall, the sampling achieved participation from a range of organisations, levels in the hierarchies, professions, and AHSN departments.

### **3.9 Data analysis**

The overall analytic strategy of explanation building (Yin, 2014) guided the steps taken to code and analyse the data. Explanation building is a specific form of pattern matching. In pattern matching predictions are compared with the findings. In explanation building, hypothesised explanations are explored and refined using the data (Yin, 2014). Single-case studies cannot result in conclusive explanations whereas multiple-case studies can confirm the explanations in a more compelling way.

As the first step, the researcher listened to all the audio recordings of interviews and observations, and then read through each transcript, document and memo several times before using “variable coding” (Miles, Huberman and Saldana, 2014, p. 100). Variable coding entailed the application of theory-determined codes, in this case drawn from the conceptual framework.

Table 3.4, Table 3.5, Table 3.6 and Table 3.7 show the structural, and functional variables, the SNA, and the effects variable (value), together with the definitions, which enabled coding consistency (Miles, Huberman and Saldana, 2014).

**Table 3.4 Structural variables, definitions and codes**

<b>Structural variable</b>	<b>Definition</b>	<b>Code</b>
Who initiates the involvement	Includes the kind of role given to the other party. The extent to which one party's motivations dominate the involvement or not. As indicated by the recruitment process.	Who initiates
Who is involved	Involvement of a diverse population, selected for the purpose.	Who involved
Diversity of mechanisms	Multiple ways of getting involved or not. Evidence that diverse groups are involved, or not.	Diverse mechanisms
Critical mass of public	Evidence of whether public contributors have peer support.	PC critical mass
Clear role definition	Evidence of written job description. Evidence of whether public contributors and staff understand public's contribution.	Written role description
Budget	Evidence of whether funds are available to support involvement or not.	Budget
Involvement reactive or proactive	Evidence of involvement permanently in place or whether it is set up to respond to events.	Reactive/proactive
Public contributors supported to meet together	Evidence that the public contributors are able to meet together, and whether they are supported.	PCs meet together
Public contributors paid for their time	Evidence of payment for time, for expenses, of vouchers in kind.	PCs paid
Training for public contributors	Evidence that training was available for the public contributors, what kind and whether they attended.	PCs trained
PPI led by a paid public contributor	Evidence suggesting who leads public contribution at the AHSN.	Contributor led
Public contributors on governing body	Evidence that public contributors are involved on the AHSN board.	Contributors on board

<b>Structural variable</b>	<b>Definition</b>	<b>Code</b>
Face-to-face involvement	Evidence of whether or not the involvement is in person, by telephone, over email or over the internet.	Face-to-face
Facilitation	Evidence of involvement being facilitated during meetings by either a separate facilitator or other meeting members.	Facilitated
Depth of the interaction	Profound, in-depth, detailed interactions. The subject matter is explored thoroughly.	Depth
Scope of the subject matter	A wide scope, where the subject matter has broad effects across multiple spheres.	Scope
Consistent set of managers	Evidence of stability and change in the professionals who are part of the projects.	Consistent managers
Involvement from the beginning	Evidence of whether or not the public were involved right from the beginning.	PCs from start
Involvement all the way through	Evidence of whether the public were involved regularly throughout or sporadically and whether they were involved right the way to the end of the projects.	PCs all the way through
Information flow	Evidence of one way (either professionals to public or public to professionals) or two way between the public and the professionals. Evidence of changes as a result or through dialogue.	Info flow
Public members contribute to official information	Evidence of public contribution to marketing communications, guidelines, training materials etc.	PCs co-create info
New initiatives are co-designed or co-produced	Evidence of jointly initiated, executed and evaluated pieces of work between professionals and public contributors.	PCs co-create

**Table 3.5 Functional variables, definitions and codes**

<b>Functional variable</b>	<b>Code definition</b>	<b>Code</b>
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<b>Functional variable</b>	<b>Code definition</b>	<b>Code</b>
Aims and objectives	Evidence of overall aims (or purpose) for the project or for the involvement from the organisations, or the individuals (professionals and public contributors). The same for objectives (ways of achieving the aims). Evidence of the impact of heterogeneity or homogeneity on aims and objectives in project team make-up. Evidence of individuals/organisations outside the project having aims and objectives for it. Evidence of implicit, explicit, hidden or false aims. Evidence of tensions between different aims and objectives. Includes evidence of public contributors' motivation.	Aims and objectives
Legitimacy	Evidence of bases for legitimacy (internal and external) including lived experience and other bases. Evidence of public contributor representativeness. Issues of professionalisation of the public. Whether or not legitimacy has an impact on the roles the public play. Evidence of discursive legitimacy. The previous experience of the professionals and the public. Thoughts on the roles of the public. Any changes to the roles with time and/or the stage of the project.	Legitimacy
Leadership	Evidence of attitudes and openness to PPI. Feedback to the contributors. Management of the tensions: management of involvement versus speed or workload or the number of other people in the collaboration. Assessment of training needs. Sensitive assignment of workload. Evidence of listening and seeking out contribution. Organising and facilitating. Setting up a relaxed and inclusive environment. Communication, persuasion and motivation. Includes negotiation, boundary spanning, teaching, coaching and mentoring. Leadership might be shown by other people, not just the chair or project manager. Evidence of whether public contribution is tokenistic or not.	Leadership

<b>Functional variable</b>	<b>Code definition</b>	<b>Code</b>
Power	Evidence of power in the first circuit, or power over: who takes the decisions; who builds the agenda; relationships to outside power structures; whether there is a power imbalance between professionals and the public; whether there are any steps to address the imbalance; whether power is being exercised, transferred or used altruistically; whether and how points of power shift through interactions; evidence that outside entities wield power. Evidence of power in the second circuit and challenges to the obligatory passage points and whether the organisation is willing to change. Evidence of the third circuit of power.	Power
Trust	Evidence of trust between individuals, between organisations, or between individuals and organisations. Whether or not there is reciprocity, or the expectation of it. Evidence of constant building of cycles of trust.	Trust

**Table 3.6 SNA, definition for and code**

<b>SNA</b>	<b>Code definition</b>	<b>Code</b>
Extent of the involvement	Answers to the network survey questions showing who each participant had meaningful discussions with, the frequency of the discussions and the subject matter.	Network

**Table 3.7 Effects variable, definition and code**

<b>Effect variable</b>	<b>Code definition</b>	<b>Code</b>
Value	Evidence of the effects and changes as a result of public contribution. Effects may be at the level of the individual, client, community, organisation or network.	Value

The conceptual framework generated 29 codes as shown in Table 3.4, Table 3.5, Table 3.6 and Table 3.7 and is within the recommendation from Miles *et al.* (2014) that the number be kept to less than 50. The initial versions of the four tables were printed out and kept in front of the researcher during coding. Any additions or refinements needed were made directly onto the printed copy and subsequently added to the record in the project database. For example, the researcher's three doctoral supervisors each coded one of the public contributor's interview transcripts

inductively. This coding exercise aimed to guard against researcher blindness to themes present in the data but not in the conceptual framework. As a result, individual motivation was specifically added to the aims and objectives code definition (as shown in Table 3.5).

Using NVivo 10, all the evidence, including interview transcripts, observation transcripts, documents and researcher memos were given a first pass code. Where necessary coding was “simultaneous” (Miles, Huberman and Saldana, 2014, p. 81), that is, the same data was simultaneously coded to more than one code. In addition, a coding consistency exercise was completed. The first transcript was duplicated before being coded. Approximately halfway through coding, the uncoded duplicate was coded again. The two attempts at coding the same transcript were then compared for consistency. This comparison was done manually, using the somewhat crude method of counting paragraphs. The result was an 87% match versus a recommended rate of 85-90% (Miles, Huberman and Saldana, 2014). Sample extracts of an interview and an observation, showing the coding results, appear in Appendix 9 and Appendix 10.

The code ‘legitimacy’ contained over 500 references after the first pass coding, making it by far the biggest single code. The majority of the references pertained to the roles played by the public contributors. A second pass coding exercise, aimed only at the references coded to ‘legitimacy’, was undertaken. The codes used were based on the phrases the participants had used to describe the public contributors’ roles. The additional codes used were: ‘boundary questioner’, ‘critical friend’, ‘don’t know’, ‘fresh eyes’, ‘keeper of public purse’, ‘lived experience’, ‘patient advocate’, ‘patient leader’, ‘occupational knowledge’, ‘occupational skills’, ‘prototype public’, ‘staff advocate’ and ‘translator’.

Once the coding was complete, the analysis made extensive use of matrices and diagrams, as recommended by Miles, Huberman and Saldana (2014). Tables captured data in short form and allowed exploration of whether suspected relationships were in fact apparent in the data (Miles, Huberman and Saldana, 2014). Where relationships were apparent, the tables appear in Chapter 4 of the thesis. Diagrams captured and displayed emerging thoughts about the relationships

between variables. Where the evidence justified these patterns, these diagrams appear in Chapter 5. The move from coded data and matrices to written findings was made using “assertions” (Miles, Huberman and Saldana, 2014, p. 99) or summary statements that captured large amounts of data. Assertions were first written and then refined, or added to until all the evidence collected under a code had been accounted for. In this way an analytic narrative was moulded. Comparisons of assertions were made across the projects for within-case analysis (Mile *et al*, p. 101).

### **3.10 Conclusion**

Yin’s (2014) case study approach has been used here as a methodology, guiding the decisions of this early career researcher. The methodology chapter presented this thesis as part of a wider research project, which informed the title, the case selection, and the case boundaries. This chapter presented the single case study of PPI at the AHSN was both an unusually good example of PPI, and as a longitudinal study as data collection occurred over a 16-month period. The embedded units design and the variation based selection of projects and participants allowed examination of the real-life operation of PPI at the AHSN from multiple perspectives. As a single case study, the only claims for generalisability from this research lie in the light PPI at the AHSN throws on theoretical propositions drawn from the extant literature. Yin’s (2014) explanation building strategy enabled the comparison of the propositions with the data through techniques espoused by Miles, Huberman and Saldana (2014) such as drawing up matrices, diagrams and making assertions. The next chapter presents the findings, structured according to the codes drawn from the conceptual framework.

## 4 Findings

### 4.1 Introduction

The findings presented in this chapter are focused on answering the overall research question: *what is the nature of PPI in inter-organisational health networks, and how is it valued?* This chapter follows the conceptual framework (see Figure 2.10) by starting with the ION as the context for PPI. The structural variables then describe the organisational intent, that is, the framework of rules, guidelines and practices governing PPI at the AHSN. At the AHSN, some structural variables applied across the PPI programme while others changed depending on the project. Next, the chapter turns to the functional variables. The functional variables show how PPI actually operated day-to-day when the public were involved in AHSN work. The evidence assembled for each functional variable is presented in its own section covering: aims and objectives; legitimacy; leadership; power; and trust. The extent of the involvement is presented next, using network maps drawn from the SNA. The maps for each project show the number and strength of the connections between the public contributors and their professional counterparts and thus the extent of the involvement. Finally the effects variable, value, shows the verifiable changes from having the public involved at the AHSN.

Table 3.3 lists the 25 research participants and the associated data sources. The evidence from each project is summarised, with illustrative verbatim quotes presented according to the following conventions. Quotes from interviews appear in italic font and are followed by the participant code. Quotes from observations are also in italic font, but the participant codes precede the quotes. Verbatim quotes have been edited to remove repetition and hesitation where this could be done without changing the meaning. Throughout the chapter, the narrative indicates when the evidence is corroborated by multiple sources.

### 4.2 The ION context for PPI

The ION context for the PPI programme at the AHSN was comprised of multiple networks: the network of organisations in the English NHS; all fourteen AHSNs; a

PPI-specific network of four local organisations; as well as the network of AHSN member organisations. The findings show that membership of each of these IONs conferred benefits, but also imposed constraints on the AHSN's PPI programme.

The influence of the wider network of NHS organisations could be seen in a number of ways. The PPI programme met the AHSN's government- set objective to involve the local community and promote collaboration, as well as delivering on the NHS-wide commitment to involvement. In common with NHS practice, the PPI manager role was scoped as a "band seven" (AH14) role. Hence, the PPI Manager at the AHSN was not a work stream director and so had to negotiate the specifics of involving public contributors with senior managers. The banding of the PPI Manager also meant that they were not on the AHSN board. However, two public contributors were. This meant the PPI Manager co-ordinating a programme where two of the public contributors were potentially better informed about strategic decisions. Organisations outside the NHS also had an effect on the programme. AH21 and AH22 were constrained in their attempt to make creative use of PC22's talents and involve them in idiosyncratic ways.

*"The problem we have and it's one of ... Revenue and Customs ... is ... there's a thin line in terms of when does a public contributor ... become a consultant ... "*  
AH21

Membership of the PPI ION, meant the resulting programme at the AHSN had "consistency" (AH22) with other members of the same network. For example AH14 reported the following common approaches: assigning public contributors in pairs, including on the governing body; the processes for selecting candidates and paying public contributors; and the templates for public contributor application forms and role descriptions. NH31 and NH22 testified that the AHSN PPI programme was advanced compared with some of the AHSN's own members such as the acute trusts. However, compared with mental health trusts, AH22 found PPI at the AHSN to have been insufficiently "radical" (AH22). The AHSN had to bring its own members and partners in the PPI network along. In AH22's view, this tied the AHSN to a pragmatic, agreed approach to PPI rather than an approach that took the most enlightened practice as the base line and improved from there.

Within the network of its member organisations, the evidence captured how the professionals in each of the projects laboured to create and maintain the AHSN's role. The AHSN courted members, a time-consuming and fallible process. Within each project, AHSN staff laboured to involve their member organisations. In P1, AH12 described trying and failing to get input from members until the department director made telephone calls. In P2, which the chair described as a “*coalition of the willing*” (NH22), the AHSN struggled to get members to attend the steering group meetings.

*“And that’s probably why it ... lacked teeth and therefore, people didn’t need to come to it.” AH21*

After a year AH22 dissolved the P2 steering group and the AHSN team looked for new ways to include both members and public contributors in the work.

NH32 gave a telling example. The P3 team set up an initiative aimed at GPs. PC32 lobbied for the inclusion of PPGs, but none attended.

*“ ... if we just opened it up to PPGs ... Some of the practices would fear that ... So it’s a sort of step by step approach and...so the baby steps are oh well let’s just get the practices in the room ... And then they came back the second time, that was a huge win ... then the next thing is well why don’t you just ask one of your patient reps to come along if you want to.” NH32*

The examples from the projects show the AHSN professionals labouring to be relevant to their member organisations by finding valuable roles to play. This labour provides part of the context in which the PPI programme, and the involvement within each of the projects took place. It appears to be consistent with a network setting despite AH13’s description of the AHSN as a hierarchy.

*“ ... it’s not really peer to peer, I mean I think it maybe is between the different groups, but there’s still a managing director you see ... ” AH13*

Just as the role of the AHSN in the network was subject to a process of negotiation, so were the roles of the professionals. The evidence showed three sets of challenges for the professionals: multiple formal roles, roles unconnected to normal duties, and the way PPI changed the roles. Many of the professional participants played

multiple roles. Two AHSN directors could have been called “clinical-managerial hybrids” (Ferlie *et al.*, 2013, p. 216) as current network managers with clinical backgrounds. Further, several professionals split their working week between roles at the AHSN and clinical roles or roles at clinical networks. The chairs of the P2 and P3 steering groups were both chief executives of hospital trusts, and members of the AHSN board. NH32 worked as a GP, at the local CCG and one day per week representing primary care at the AHSN. In fact, NH32 attributed the openness of the AHSN staff to PPI to their varied professional experience, comparing it to the relative resistance to PPI of general practice.

*“... if you look at the people working here now, if you said ‘Well what jobs have you done in the last five years?’ ... They’ve actually done a massive amount of jobs. And someone then like myself are doing three jobs ... in the same week ... whereas back on the coal face, you know, sometimes you’ve got people been sitting at the same desk for 25 years.” NH32*

The professionals also played roles not in their formal job descriptions. For example, in P1 all three professionals played roles for which they had not been hired. AH11 and AH13’s jobs were both directed at industry partners until they were drafted onto P1. AH12’s job engaging members was extended to cover managing CO, with responsibility for the project’s PR and thus the level of engagement with the general public. The overall finding here is the fluidity of the AHSN’s role and of the roles of the professionals.

The extent of the negotiation between organisations and individuals in the IONs was expected to provide a beneficial context for PPI. If professionals used network-based soft skills, then the findings should show evidence of feedback to public contributors. In P1, the evidence of feedback to public contributors came from emails. One email thanked all the team members (including the public contributors) for providing input to materials. Another email, signalling the final P1 teleconference, thanked PC11 and PC12 for their help in the project.

In P2, PC22 spoke about receiving feedback on their contribution.



*“I suppose they have been quite nice I suppose in terms of, I have had feedback about just - being positive, thank you for doing that, it was really good when you did this, thank you for being involved in this ... ”* PC22

In some circumstances, PC22 could see their suggestions put into practice, for example at the AHSN conference.

PC32 described a sporadic and indirect approach to feedback during their two years attending quarterly P3 meetings. After an early meeting, two AHSN staff members credited PC32 with ensuring the success of an initiative.

*“ ... I asked one of my idiotic questions, and ... [two members of AHSN staff] came up to me at the next board meeting and said that question you asked that turned the tide for everybody, they've all signed up now.”* PC32

Indirect feedback came in two ways. First, the AHSN supported PC32’s successful application for some training. Second, at the end of the two-year contract, the AHSN asked PC32 to stay on as a public contributor to P3 for another year. As PC32 pointed out, the feedback mechanism could be more regular and more formal.

*“I suppose the only thing is it would be good to have some feedback to public contributors ... I assume if I hadn’t been meeting the brief...then they wouldn’t have asked me to have continued for another year.”* PC32

At interview, AH32 described feedback for PC32, although PC32 didn’t mention having received it.

*“A lot of people have actually sort of recognised [PC32] now ... [PC32’s] input ... and we even had people that say ‘Is [PC32] gonna be there?’”* AH32

None of the other participants interviewed spoke about receiving feedback on their contribution. Neither did observation provide any data. In summary, AH14 provided the formal contract review as the two-year term expired. Individuals from P2 and P3 provided some sporadic, informal and sometimes indirect feedback.

Structural variables – overall PPI programme

Table 4.1 Structural variables for the overall PPI programme below summarises the structural variables pertaining to the overall PPI programme at the AHSN. The

structural variables capture the AHSN’s intent for PPI, focusing on the organisational practices, regulations and guidelines governing how PPI is conducted.

**Table 4.1 Structural variables for the overall PPI programme**

<b>Structural variable</b>	<b>Overall PPI programme at the AHSN</b>	<b>Sources</b>
Who initiates the involvement	The AHSN initiated involvement through advertising for public contributors, selecting them from applicants, and matching them with projects.	Interviews with AH14, PC22, PC32.
Who is involved	All six public contributors were people with current or past professional backgrounds.	Interviews with AH14, PC11, PC12, PC22, PC31, PC32 and observation of PC21.
Diversity of mechanisms	Involvement of the contributors was through attendance at the AHSN board, and project steering groups meetings. However other forms of involvement were available through workshops, training and events.	Interviews with AH14, PPI newsletters, PC11, PC32, PC31.
Critical mass of public	The AHSN assigned two public contributors to each project, and to the AHSN board. However, one contributor (PC21) dropped out of P2, leaving only PC22.	Interview with AH14, and observation in P1, P2 and P3.
Clear role definition	The AHSN deployed a written role description saying that public contributors should: <ul style="list-style-type: none"> <li>-Be a critical friend (although this term was not explained).</li> <li>-Plan workshops (P1 only).</li> <li>-Review materials.</li> <li>-Prepare for meetings.</li> <li>-Other agreed activities.</li> <li>-Promote the AHSN.</li> <li>-Support new public contributors.</li> </ul>	Role description documents for P1 and P2.
Budget	Budget deduced from presence of PPI manager, events, and payments to contributors.	Interviews with AH14, documents, and observations.

<b>Structural variable</b>	<b>Overall PPI programme at the AHSN</b>	<b>Sources</b>
Involvement reactive or proactive	Involvement proactive on the AHSN board, and in P2 and P3. Involvement reactive for P1 and short-term.	Interviews with AH14 and observations of P1, P2, and P3.
Public contributors supported to meet together regularly	Public contributors invited to meet with the AHSN (separate to their projects) every six months.	Interviews with AH14, PC11, PC22, PC32.
Public contributors offered payment for their time	Payment of £20.36 per hour, and travel expenses of £0.45 per mile.	Documented on role description documents.
Training for public contributors	Induction provided to introduce the AHSN, and its different work streams.	Interviews with PC11, PC32
PPI led by a paid public contributor	PPI programme led by a PPI professional rather than a public contributor in a paid role.	Interview with AH14.
Public contributors on governing body	Two public contributors attended the AHSN board.	Interviews with AH14, PC32.

Most of the structural variables that applied to the overall PPI programme were positively associated with effective PPI in the literature review. However, there were three exceptions. The initiation of PPI was solely by the AHSN, not shared with the public nor initiated by them. Leadership of the involvement was by a paid professional, not a paid public contributor. In addition, the data in Table 4.1 prompts questions about the diversity of the contributors. The AHSN selected candidates based on their ability to join senior NHS professionals in formal meetings, but the result was six individuals all from white-collar occupational backgrounds, whereas the literature review associated effective PPI with the involvement of a diverse public.

### **4.3 Structural variables – project specific**

Some of the structural variables identified in the literature review varied across the three projects. Thus within the PPI programme, the projects agreed approaches with the PPI Manager that suited their particular work, timescale, or geographical challenges. Table 4.2 below summarises those structural variables applicable to each project. In some cases, the data are definitive. In other cases, the evidence provided

is relative and provides a comparison between the three projects. To facilitate the comparison between the three projects, Table 4.2 presents the findings from each project together.

**Table 4.2 Structural variables specific to the projects**

<b>Structural variable</b>	<b>Project 1 (P1)</b>	<b>Project 2 (P2)</b>	<b>Project 3 (P3)</b>
Face-to-face involvement	Involvement was primarily through teleconferences with two face-to-face meetings.	Involvement was through face-to-face meetings although there were occasional catch-up telephone calls between an AHSN staff member and public contributors.	Involvement was through face-to-face meetings.
Facilitation	Teleconferences chaired by AHSN project manager.	Steering group meetings formally chaired by an appointed senior NHS manager.	Steering group meetings formally chaired by an appointed senior NHS manager.
Depth of the interaction	The combination of the speed of the project with meetings via teleconferences tended to force discussions to be relatively superficial.	The steering group meetings tended to force discussion to be relatively superficial.	The P3 sub-projects allowed one public contributor to pursue their interests to considerable depth compared to P1 and P2.
Scope of the subject matter	Narrow relative to P2 and P3 as a single programme.	Wide relative to P1 as it covered multiple programmes. Similar to P3.	Wide relative to P1. Similar to P2 in that it covered multiple programmes.
Consistent set of managers	Entire project team the same throughout the public involvement, although the AHSN project manager left the AHSN soon after this and before project completion.	AHSN project team consistent throughout data collection period. Attendees from member organisations varied over the quarterly P2 meetings.	AHSN project team consistent throughout data collection period. Attendees from member organisations varied over the quarterly P3 meetings.
Involvement from the beginning	Public contributors involved from the first teleconference.	Public contributors involved from the first P2 meeting.	No data.

<b>Structural variable</b>	<b>Project 1 (P1)</b>	<b>Project 2 (P2)</b>	<b>Project 3 (P3)</b>
Involvement all the way through	Involvement of the public contributors finished before the project ended.	Involvement all the way through.	Involvement all the way through.
Information flow	From public to professionals and professionals to public.	From public to professionals and professionals to public.	From public to professionals and professionals to public.
Public members contribute to official information	P1 leaflets and posters reviewed and changed by public contributors.	No data.	No data.
New initiatives are co-designed or co-produced	No work jointly initiated, executed and evaluated.	No work jointly initiated, executed and evaluated.	No work jointly initiated, executed and evaluated.

Not all of the data collected in relation to the project-specific structural variables were associated with effective PPI in the literature review. P1 used mainly teleconferences rather than face-to-face meetings, the depth of the interaction was relatively superficial, the scope was relatively narrow, the involvement of the public contributors ended before the project did and none of the work was jointly initiated, executed and evaluated. P2 also had relatively superficial interactions (although the AHSN staff and the public contributors were planning future in-depth involvement with PC22). None of the P2 work was jointly initiated, executed and evaluated which also held true for P3.

The data collected from the three projects, revealed structural variables that did not appear in the conceptual framework. These are summarised below: -

- Speed – all the professional participants acknowledged the speed at which P1 was carried out. Both PC11 and PC12 raised the tight timescales as an impediment to public contribution.
- Professionals' experience of PPI – only one of the professionals in P1 had previous experience of involvement. Some of the P1 professionals had experience of public engagement rather than involvement. The professionals in P2 and P3, on the other hand, had experience of involvement from other health settings.
- External parties – P1 included professionals from organisations outside the NHS, and outside health and social care and with no background understanding of PPI. The professionals in P2 and P3, on the other hand, were exclusively from health and social care organisations.
- Engaged versus involved publics – P1 involved the public contributors (PC11 and PC12) in a project aimed at engaging members of the general public using promotional materials, and persuading the public to participate in generating ideas. However, the P1 professionals struggled to distinguish between the public contributors working with them on the implementation and the engaged public attending the workshops. P2 and P3, on the other hand, involved their public contributors, but were not working with any other form of public.

- Involvement frequency - whereas the P1 team met weekly, the P2 and P3 teams met quarterly.
- Project duration - P1 lasted only four months, P2 lasted for a year and P3 had been running for two years by the end of the data collection period

#### **4.4 Functional variables - aims and objectives**

The first functional variable, showing how PPI at the AHSN operated and was experienced by public contributors and professionals, is the aims and objectives. The data reveal a plethora of different aims and objectives at the network.

##### **4.4.1 Aims and objectives – P1**

The original P1 project documentation, shared with AHSN member organisations, revealed its aim to be the first of three projects providing a channel for members of the public to work with the NHS and businesses to form solutions for healthcare problems. The major project objectives were engagement with the public through the media and community groups and then participative workshops. The document detailed the inclusion of the network members, a public relations (PR) firm (CO), and a charity (SE) but not the involvement of the public contributors.

Beneath the project level aims and objectives, the individuals in P1 revealed a divergent set of objectives perhaps because the membership of P1 was diverse. The P1 project team meetings encompassed the AHSN, SE and CO plus the public contributors (PC11 and PC12). The tight schedule may also have reduced the time available for consensus building. Consequently, the professionals exhibited different objectives. For example, AH13 reported that the AHSN director responsible saw P1 as primarily an open, online, interactive project. SE, on the other hand, had conducted live workshops before and saw these as the main vehicle. AH12 experienced a similar difference with CO, expecting them to achieve widespread online engagement, but finding instead that they concentrated on promoting the live workshops. In turn, CO11 reported that the AHSN had underestimated the time it takes to build online engagement.



The public contributors had different aims from the professionals, and from each other.

*“And ... after [prior AHSN project] that I thought, okay, actually that just felt like quite a good thing to do, to give back to the NHS a little bit.”* PC11

By contrast, PC12 pursued a specific set of aims including assistance with their own research project and improvements for the local group for their own condition.

*“I’m doing research myself and ... my topic is related to [condition] as well. My research ... so I’m broadening myself as well, you know. Trying to get involved in it and also it’s to help ...”* PC12

PC12 didn’t just attend the P1 meetings to achieve their aims. Rather, PC12 put together leaflets for their local group, posted items on social media, promoted the local workshop, and collected ideas to bring to the pilot workshop. Perhaps the specificity of PC12’s aims made compromises inevitable. None of the selected designs aided PC12’s local group, or sufferers from their condition. Neither did PC12 find a way to add this to any P1 meeting agenda or to influence the selection process. The AHSN project team, though, did introduce PC12 to another team whose project catered directly for PC12’s condition. Thus the professionals at the AHSN negotiated a possible way for PC12 to achieve their aims, through contact with other parts of the organisation rather than directly through public involvement with P1.

#### **4.4.2 Aims and objectives – P2**

The strategy documents produced for P2 revealed the official aim of the project, to bring all the AHSN work in this particular area together to meet the needs of the AHSN and its member organisations. The objectives in this document detailed the way this aim was to be fulfilled. P2 was to align with national developments, to secure high-level support from member organisations, to provide a multi-stage pathway, to form a network of individuals, to provide resources and support centrally, and to develop a communication strategy to support the initiative. The strategy document mentions PPI as a topic area for P2 to cover, not as a specific objective, but rather as a way of getting the work done.

Unlike P1, the data collected from P2 did not reveal a range of divergent objectives. However, the P2 meetings suffered from limited attendance by member organisations and (except for the first quarterly meeting) had only one public contributor. PC22 spoke of a broad motivation to get involved in healthcare.

*“So I was involved because ... sometimes doctors say things to me and I say that's ridiculous, you need to do this ... And so one of my doctor friends said you know there's a public involvement role at ... you should do that, you'd be good at that, you have opinions about everything.”* PC22

Like PC11, PC22's aims seemed likely to be fulfilled by effective involvement in any AHSN project. In terms of objectives, PC22 had not wanted to be involved via committee, but ended up on one. However, the “*maverick*” (PC22) nature of the P2 AHSN team, and AH22's personal approach compensated. After a year, when AH22 dissolved the P2 steering team, PC22, AH21 and AH22 agreed to meet monthly to work on more strategic planning items. Again, the AHSN held out a possible future way for PC22 to meet both their aims and their stated objectives.

#### **4.4.3 Aims and objectives – P3**

The terms of reference for P3 detailed the aim for the project, to improve in this area across the regional NHS. The supporting objectives listed a region-wide learning and improvement system, support for individual improvement projects, working with partners and national schemes, supporting positive cultural change and developing patients as co-leaders. The governance section of the document included two patient leaders on the programme board, as well as representatives from all the member organisations. From the start, P3 was conceived with public involvement as both an aim and as part of the process.

PC31 wanted to work on a committee.

*“I'm a bit of ... a health committee junkie really to be perfectly honest.”* PC31

Both PC31 and PC32 had specific areas of interest. But PC31 was not working in their area of interest, the computerisation of medical records. In their application for the involvement roles at the AHSN, PC31 did not state this interest.

*“I thought I stood a better chance if I said I didn’t have any preference.”* PC31

PC32’s previous job and voluntary work directly related to the work of P3. This alignment of interest and involvement may explain why PC32 contributed more often than PC31 at P3 meetings.

*“ ... they [PC32] probably [do] 85, 90 per cent of our public contributions ... ”*  
AH32

PC32 aimed to cajole P3 into taking a more holistic view of patient care by extending the work from acute trusts out to both general practice (GPs) and care homes. Once a forum for primary practice had been set up as a sub-project, PC32 then agitated to require the GPs to involve their patient participation groups (PPGs).

*“ ... what I'd like to have is a bit more input into the [P3 sub-project]. I had to miss the first meeting when they came together because I was away ... but I'm going to the next one. Because what I've been pushing for, and you might have heard me say it at the board meeting is that we need to involve their patient participation groups in the GP practices to be part of the collaborative work.”*  
PC32

PC32 pursued aims relevant to their own background, well matched to the work of P3, and fitting to the capability and intent of a network organisation. Although this confluence did not mean that PC32 achieved all of their aims.

#### **4.5 Functional variables - legitimacy**

Legitimacy is the second functional variable. This section focuses on the public contributors, their uncertainty around their roles and how they established their legitimacy through playing a wide range of roles.

##### **4.5.1 Legitimacy - uncertainty about the role of public contributors**

Four out of the five public contributors interviewed expressed uncertainty about the roles they had played or were supposed to have played in the three projects studied. These three contributors came from each of the three projects. In P1, PC11 expressed their doubts.

*“I think we talked about it actually, when we had a sort of patient participant public meeting, that sometimes it's not very clear what you're supposed to be doing. What is your role? ... It still wasn't very clear what sort of difference we could make, what they wanted us to say.”* PC11.

PC11 described the written job descriptions as listing the timing commitments, and the way to claim hours and expenses rather than describing the nature of the contribution. The AHSN held an induction event where the 12 AHSN public contributors could meet each other and where the AHSN professionals taught the public contributors about the AHSN organisation, and each of its departments. PC11 described their thoughts after that meeting.

*“It can be very important because the public are the people who it's all being done for, really ... You need to have ... not just people who've been through very specific situations, but people who ... can give a non-professional point of view.”* PC11.

However, the induction did not resolve PC11's doubts. Some of the uncertainty arose as they didn't feel qualified to speak, despite a background in media that was relevant to the way the project was advertised and promoted to the general public, being a carer, and despite having contributed to a previous AHSN project. PC11's co-contributor on P1 expressed no such doubts. PC12 saw themselves as playing multiple roles: demonstrating someone managing their condition, as a professional from another sector, and as someone engaged in research (PC12 was undertaking a doctorate).

In P2, PC22, while they could describe the role they had played, felt that its value was small, even negative. They said

*“ ... but I think that ... really do they not just get in the way, public contributors of ... what needs to be done? Apart from ... the ones who have had direct experience of the service ... ”* PC22.

In P3, PC31 said they didn't know “*what to bring up*” or what they added.

*“I'm not sure what the patient, what the public contributors... what added value they bring to some extent ... ”* PC31.

PC31 wondered if, other than lived experience, the public contributor role was worth doing. They described the 2014 Care Act as resulting in widespread but unthinking public contribution.

*“And so they’ve all sort of ... jumped on the bandwagon ... without really knowing what they’re doing quite honestly.”* PC31.

Observation of the limited interjections made by PC31 in P3 meetings reinforced the uncertainty they spoke about. PPI at the AHSN was an environment characterised by PC32 as uncertainty on both sides.

*“I mean maybe they weren't quite sure what to expect from the public contributors either and, you know it's both sides learning as you go along isn't it?”* PC32.

Professionals in the study also voiced concern about the role of the public. As AH13 pointed out, engagement from the general public, rather than contribution from PC11 and PC12, was the focus in P1. Answers to interview questions tended to describe the public who had attended workshops rather than the public who had attended planning meetings. This was especially noticeable from professionals employed outside the AHSN. SE11, SE13 and SE12 (all professionals from a charity) did not distinguish between the roles of the engaged public and the involved public (PC11 and PC12). None of them articulated a role for the public besides attending the workshops, even though PC11 and PC12 attended the pilot workshop.

In P2 and P3, NH21 and NH31 both echoed PC31’s concerns that the requirement to involve public contributors had moved ahead of developing a role for them to play.

*“I'm always very conscious about the sense of tokenism ... You know the sense that we have two patients around the table, we can tick our boxes, and okay we've done patient involvement.”* NH31.

One participant voiced the idea that uncertainty around the public contributor role might be a good thing, that it might leave the contributors and the professionals free to negotiate a mutually beneficial relationship.

“Why are we trying to box people in, in PPI?”... Why can’t we negotiate adult-to-adult conversations about what is it you want to do? Does that fit with the organisation’s needs? How do we work together to build a relationship that both have benefit from?” AH22.

#### 4.5.2 Legitimacy - the range of roles played by the public

Despite the widespread uncertainty, participants articulated a range of possible roles for the public. All the public contributors, including those who expressed disquiet, were observed playing a range of roles. Paraphrasing, the roles identified by the participants during interviews were: provider of lived experience, patient leader, creative, non-executive, critical friend, collaborator on service delivery and redesign, group representative, learner, provider of an external view, legitimiser of the money spent on the NHS, volunteer, patient advocate, trainer, fresh pair of eyes, team member, co-designer, co-producer, holder of a looking glass, manager of the NHS by the people for the people. The participants also described a set of less positive roles: rubber stamp, tick box, token, axe-grinder, professional committee member, provider of justification for public spending on the NHS. Some of these roles were only described, either as ideal types, anecdotes, or from previous experience. The roles that were both described by participants and observed in meetings can be organized into three groups, as shown below in Table 4.3.

**Table 4.3 Categorisation of roles**

<b>Group 1 Roles determined by the background and experiences of the public contributor</b>	<b>Group 2 Roles determined by the nature of the work the public contributor is involved in</b>	<b>Group 3 Roles any motivated public contributor can play in any sort of NHS work</b>
Lived experience	Prototype public	Fresh-eyed reviewer
Occupational knowledge		Patient advocate
Occupational skills		Critical friend
		Keeper of the public purse
		Boundary questioner

In order to play any of the group 1 roles, the public contributor brought their own background and experience to bear. This group of roles included not only lived experience as a patient and carer, but also skills and knowledge learnt from occupations and interests. Group 2 roles were permitted or limited by the nature of

the work the public contributor was involved in. For example, only P1 allowed the public contributors to try out resources aimed at the general public because only P1 aimed resources at the general public. In this thesis, only the prototype public fit within this group. The potentiality to play group 3 roles existed for any public contributor in any project at the AHSN. No individual public contributor played all the roles listed here. However, individuals did play multiple roles within the same project, often within the same meeting.

#### 4.5.3 Legitimacy - group 1 - lived experience

Lived experience as a patient or a carer dominated the data. Eighteen of the 25 participants described a lived experience role. Four public contributors observed played this role, even though none of them worked on projects directly relevant to their own health.

**Table 4.4 Showing instances of observed contribution based on lived experience**

<b>Participant</b>	<b>Instances of lived experience contribution observed</b>
PC11	Contributed experience as a carer to the P1 pilot workshop.
PC12	Contributed experience as a patient to the P1 pilot workshop.
PC31	Contributed experience as a patient to the P1 pilot workshop.
PC32	Contributed experience as a carer while giving feedback on a programme to train healthcare assistants.
PC32	Backed up the importance of ancillary staff and their training, based on their own experience as a carer.

The professionals provided rich descriptions of the lived experience role for public contributors. Several professionals noted that contributions from the public could remind professionals what it was really like for patients. Professionals can become comfortable working in health settings like hospitals and forget how overwhelming they can be. They can sometimes miss the things that really matter to patients. Several professionals outlined the valuable assistance patients provide in service redesign or any improvement activity. A benefit, described by one participant (AH33), is that the involved patients also developed a keener understanding and sympathy towards the constraints such as budget and timescale. AH22 described a role for patients with lived experience as peer trainers for other patients with a condition. This professional also painted a vision for the future where patients trained in quality improvement techniques lead improvement projects in the NHS.

The public contributors added more detail. PC12 wanted to show that patients could own their care, make a contribution and develop expertise. PC31 thought that lived experience helped with motivation, saying that the public are more likely to be interested if the procedure is one they might need. PC12 spoke of promoting P1 to a local condition-specific group: producing a leaflet, giving updates at meetings, and promoting the workshops. Several professionals assumed that all public contributors disseminated their activities amongst their community. NH21 said,

*“...I think if people who’re coming bring other people’s views as well as their own then that helps.”* NH21.

However, of the five public contributors in this study, only PC12 reported doing this. PC32 explicitly addressed this issue.

*“Where with the public contributor role there isn't the necessity to go back to your contacts, your networks if you like, to ask people's opinion.”* PC32.

PC11, PC22 and PC31 all felt that the lived experience role was more worthwhile than the general citizen contributor. PC11 said,

*“I wondered if their sort of patient participants maybe should have been people who had, you know, had a bit more of a need for some of the products they were going to be making ... ”* PC11.

While acknowledging the power of lived experience, the professionals also expressed some concerns. Several contrasted patients who only “moan” (AH32) with those who were constructive with their criticism or also said something complimentary when things went well.

*“It’s just giving us examples of times that [they’ve] perhaps been unhappy with the service [they have] received ... so often I think sometimes people feel like they have to contribute because ... they’ve got something to say and they wanna get it off their chest, rather than contribute to ... helping us move forward.”* AH24.

Patients who focus exclusively on their experience, and who do not contribute to the work at hand are described variously as having an “agenda” (NH32 and NH21) or “an axe to grind” (NH21). NH21 reported an incident from their past.



*“...there were a couple there who’d been invited as patient representatives. And in the middle of something which was nothing to do with what we were talking about, stood up and talked about their own experience and taken out of context like that it was very difficult for the speaker because you don’t want to say actually we’re not talking about this at the moment...” NH21.*

The professionals variously narrated how, in previous experiences of PPI, they had seen narrow or badly timed contributions do damage. Patients may expect a response from the meeting that is not in its power. Professionals wasted time and resources managing someone who never intended to be constructive. Meetings became less productive and less honest because professionals became defensive and were reluctant to open up about mistakes. More than one professional noted that the best contributions came from people who could generalise their experience out to other patients. NH21 felt that involvement failed to attract contribution from people who have *“had a good or a just good enough”* (NH21) experience and who could contribute *“a whole swathe of unsaid things which could really make a difference”* (NH21). On the other hand, as related by NH21, some of the most compelling stories of patient-driven change in the NHS came from patients or carers who had a particular focus, and who refused to give up.

The lived experience dominated the data here despite the AHSN’s expectation that the public contributors would play strategic roles on steering committees. In fact AH14 described this strategic role in contrast with the lived experience role.

*“ ... it’s quite good to differentiate between ... people ... who can ... participate in ... an advisory group or a steering group ... who ... perhaps have the skills that we need to carry that project forward ... there’s a different type of ... public contributor that might be more about bringing their lived experience of a condition ... and there we would be looking for them to be able to share the information about their condition ... ” AH14.*

Many professionals reported experience of PPI based on strategic boards and committees. In particular most study participants from the wider NHS, rather than the AHSN, had this background.

**Table 4.5 Previous experience of NHS professional participants with PPI**

Participant	Previous experience involving service users
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<b>Participant</b>	<b>Previous experience involving service users</b>
AH23	Patient and public representatives on governance boards and committees.
NH21	Patient and public representatives on various boards at the CCG.
NH22	Patient and public governors on the foundation trust board.
NH31	Patient and public representatives on various committees.

However, seeking lived experience from the public was an established routine for many of the professional participants. SE11, SE12 and SE13 sought user input as a standard part of their design process and saw P1 in the same terms. These participants struggled to distinguish between PC11 and PC12's contribution and that of users who attended the workshops. For SE11, SE12 and SE13 the focus of the role PC11 and PC12 played was their testimony as carer and patient.

**Table 4.6 Previous experience of professionals from non- NHS with PPI**

<b>Participant</b>	<b>Previous experience involving service users (lived experience).</b>
SE11	None – although design process included public engagement.
SE12	None – although design process included public engagement.
SE13	Members of the public were involved in the process, outputs and conduct of research.
CO11	None – although had worked on a project to engage the public with sport and exercise.

Similarly, the AHSN professionals spoke of an established background in lived experience. For the AHSN staff in P1, this background was not strictly in public involvement. These participants described public engagement based on lived experience. In P2 and P3 AHSN and other NHS staff reported extensive familiarity with involving the public for their lived experience.

**Table 4.7 Previous experience of NHS professionals of PPI with service users**

<b>Participant</b>	<b>Previous experience involving service users (lived experience)</b>
AH11	None – but had included the public as participants in research projects.
AH12	None.
AH13	None – but had engaged the public for an education project.
AH21	None.
AH22	Co-production with service users.
AH23	Service users' care.
NH22	Reconfiguring services in a local town.
AH24	None.
AH31	New build of a hospital department, and refits of two other departments.

<b>Participant</b>	<b>Previous experience involving service users (lived experience)</b>
AH32	Transfer of a hospital department as part of a hospital closure.
AH33	Service users in groups and forums.
NH32	PPG.

#### **4.5.4 Legitimacy - group 1 - occupational knowledge**

All of the public contributors came to involvement with occupational knowledge of their own. The instances of contribution included in this role were those where the public interjected based on their previous jobs or voluntary experience. The professional participants themselves acknowledged the public's occupational backgrounds.

*“I’m treating them as professional people really, you know they might not be in the health care service, they might be insurance brokers ... or policemen or something like that but you know they would still interact at a professional level.”* AH13

AH14 selected public contributors with professional backgrounds. Surprisingly, then, only PC22 and PC32 were observed deploying their own occupational knowledge.

**Table 4.8 Instances of occupational knowledge**

<b>Participant</b>	<b>Instances of observed occupational knowledge</b>
PC22	Used their marketing experience to point out that the professional team was using the name and brand of P2 inconsistently.
PC22	Introduced themselves at the first P2 meeting by saying what their (non-medical) professional experience was.
PC32	Used definitions of the terminology from their past (medical) experience.
PC32	Talked about a way to extend the current work, drawing on an attempt made in their past job which covered the same responsibilities as P3.
PC32	Checked to see if the speaker was aware of a decision tree used in the past, from experience in their past job which covered the same responsibilities as P3.
PC32	Used direct experience doing Enter and View with Health Watch to point out a problem that had been reported with regard to deafness and foreign language patients and available skilled administration staff.
PC32	Added to a discussion with knowledge from Health Watch on the way Do Not Resuscitate was handled in another part of the country. And the pitfalls of processes held in an office when the event happens in the bedrooms in the middle of the night.

<b>Participant</b>	<b>Instances of observed occupational knowledge</b>
PC32	Volunteered a way of giving nurses the motivation to be involved in some training by linking it to their revalidation, from their own direct previous experience.
PC32	Used their own direct knowledge of the history of issues around insulin administration to ask why this was still a problem and to challenge whether the current work would really address it.

PC11 explained that they had been matched to P1 partly because of their media background. This led to what they described as their most valuable contribution, pointing out the newsworthiness of the launch event, subsequently covered on the local evening news programme. However, they also reported holding back on occasions. The project had engaged CO to do PR and PC11 said that it was not their place to challenge CO or make suggestions. They went on to express doubts about the P1 social media campaign that had not been sustained and frequent enough to really establish itself. There is no evidence that PC11 voiced these doubts either in email or at any of the project meetings. Perhaps one of the limits of the occupational knowledge role for the public contributor exists where the project has an official expert already on the team. Interestingly, PC11's background in the media did not prevent them from feeling unqualified as a public contributor to P1.

*“I didn't feel that ... my professional side was going to be hugely helpful on this project,”* PC11.

PC22 explained their occupational knowledge as a natural, inseparable part of who they were. Marketing also represented the most valuable thing PC22 could offer, especially in the NHS where it was in short supply and often regarded as “*a dirty word*” (PC22) associated with selling.

*“ ... but actually everybody needs a way of communicating, everything from the flu jab ... ”* PC22.

The frustrations for PC22 arose from not being able to contribute their marketing experience freely due to the budget for public contributor's time and not wanting to “*overstep the mark*” (PC22).

*“I mean in my old life as a consultant, if [AH21] had come to me and said we need some help in [P2] it's comical almost to think how much more effective we could have been together.”* PC22.

On the other hand, PC22 felt that offering marketing expertise for the rate of pay offered to public contributors meant a good deal for the NHS.

*“And you get me cheap so I suppose that's going for it, you get me really cheap.”* PC22.

One participant outlined this as a specific form of civic contribution.

*“ ... you want a relationship with an organisation ... you don't want to get the full market value for your skills.”* AH22

However, the occupational role for public contributors caused headaches for the AHSN, not least with Her Majesty's Revenue and Customs (HMRC). AH21 reported the need to negotiate the rules governing when a public contributor becomes a consultant and said this had caused *“interesting debates within the project”* (AH21). AH21's own position echoed PC22's: the best value could be gained by making the most of PC22's specialist experience.

PC32 brought not only healthcare experience as a nurse and midwife, but prior to retirement had worked in a role directly relevant to P3. Volunteer work for Health Watch gave them a working understanding of care homes. Not surprisingly, PC32 said that this background gave them useful expertise to draw upon. In particular, the observations showed PC32 signposting resources developed during their time in a relevant post. These interjections reflected PC32's dismay when NHS staff seemed to keep *“reinventing the wheel”* (PC32). PC32 hoped to jog the NHS into becoming *“an organisation with a memory”* (PC32). PC32 also recognised the potential downside.

*“But it's difficult isn't it? As though you're trying to say in my day we did things better ... ”* PC32.

Views amongst the professionals were split. NH21 worried that PC32's medical background prevented them from being an effective voice of the patient - although

the observations in this study showed PC32 playing both a lived experience and a patient advocate role. Two other professionals spoke in favour. NH32 saw PC32’s medical background as permitting greater scrutiny of the NHS. AH32 felt it enabled PC32 not only to critique work, but to make suggestions as well.

A background in healthcare did not always facilitate public contribution. PC31 had occupational knowledge as a medical summariser, and described using this to understand the terminology. In addition PC31 had volunteered at their local Health Watch. However, PC31 was not observed using this background in P3, although the opportunities were also fewer as unlike PC32, PC31 attended no sub-project meetings during the data collection period.

#### **4.5.5 Legitimacy - group 1 - occupational skills**

This role is closely related to the provider of occupational knowledge. However, the instances included in this role were the ones where the public contributor used the skills built up as a result of their job, rather than direct, job-specific knowledge. PC21 summed up this role at the inaugural P2 steering group meeting. Having introduced themselves as an employment lawyer, they said this gave them an eye for technical detail. As shown below, PC21 did not offer P2 advice on the law, but this eye for detail. Similarly, PC22 introduced themselves as a former communications specialist and now a writer. Thus, as PC22 explained, their commentary on e-training options was not based on direct professional knowledge of training. Rather, their writing and communication skills allowed PC22 to critique the delivery of training for the professional team and to encourage more appropriate use of words to avoid sounding “*old-fashioned*” (PC22) and “*pompous*” (PC22). Even reviewing papers in advance of meetings, and reading widely around a subject, as PC32 reported doing, can be regarded as skills honed over many years in some occupations.

**Table 4.9 Instances of occupational skills**

<b>Participant</b>	<b>Instances of observed occupational skills</b>
PC21	Pointed out that the basis of the comparison between training resources was not consistent, using the eye for technical detail developed as a lawyer.

<b>Participant</b>	<b>Instances of observed occupational skills</b>
PC21	Asked what the budget to fund a programme was, using the eye for technical detail developed as a lawyer.
PC22	Expressed their views on the effectiveness and acceptability of e-learning resources, using their communication skills developed in marketing jobs.
PC32	Talked about ways of sharing knowledge, and suggested a wiki, a tool they had used in a previous occupation.

The potentiality to play the group 1 roles proceeds from the public contributors' own backgrounds. All the public contributors possessed qualifications to play all three roles. However, only PC32 actually played all three roles. Thus most of the public contributors had the potential to fulfil roles they did not play, representing a loss of possible contribution. While most of the professionals talked about the lived experience role, rather fewer acknowledged the occupation-based roles. In particular, in P1, only one professional acknowledged the occupational knowledge or skills of the public contributors in any way. PC12, on the other hand, had specifically spoken of educating the professionals in the number of roles a patient with a chronic condition could play.

#### **4.5.6 . Legitimacy - group 2 - prototype public**

Sometimes the nature of the project determined the roles a public contributor could play. In the prototype public role, the public contributors trialled resources in advance of a launch to the general public. In this thesis, only P1 offered the opportunity to play this role. Thus PC11 and PC12 acted as prototype publics, and so did PC31 but only on attending the P1 pilot workshop.

**Table 4.10 Instances of the prototype public role.**

<b>Participant</b>	<b>Instances of observed prototype public</b>
PC11	Attended P1 pilot workshop.
PC11	At the pilot workshop, asked the workshop leader whether workshops would be split up into groups, and how quickly, and offered their view that sitting in the same place for 2 hours might be too long.
PC11	At a steering group teleconference, asked if the public could attend workshops without registering so that the public could decide to attend on the day and did not have to commit in case, for example, the day turned out to be very rainy.
PC11	At a steering group teleconference, pointed out that the pilot run workshop had worked better when the group had split up, rather than at the plenary session.

<b>Participant</b>	<b>Instances of observed prototype public</b>
PC11	Provided feedback on logo colours and ‘look’ of branded materials.
PC11	By email suggested changes to the wording of the draft poster to encourage more people to attend.
PC12	Attended P1 pilot workshop.
PC12	By email confirmed that the draft poster did not need to change.
PC31	Attended P1 pilot workshop.
PC31	At the P1 pilot workshop, asked whether a resource at the pilot workshop was going to be used.
PC31	At the P1 pilot workshop, asked what would happen next in the P1 schedule after the workshops, and in a series of prompts pushed for more detail.

One of the ways the public contributors played this role in P1 was through attending the pilot workshop. The public contributors stood in for the general public. From the pilot, the professionals assessed how well the workshops functioned. However, as the observations in Table 4.10 show, both PC11 and PC31 took this role a step further, by indicating their own assessments of how well the workshops functioned.

Three professionals from P1 outlined their view of this role, summarised by AH12 below.

*“So I think it’s their... knowledge of if you do it like this it probably might reach more people ...”* AH12.

In P1, the AHSN staff saw the public role not only as fundamental, but also as providing legitimacy.

*“I think it certainly added a lot of legitimacy to the project because ... it would be probably a bit cheeky that the citizen led project without any citizens on ...”* AH11.

Two clear downsides emerged for those playing the role of prototype public. First, the feedback could become a rubber stamp.

*“ ... I think it was a validation thing more than ... anything ... ”* AH12.

Second, the role, while clear at the start of a project, could fizzle out. SE11 stated that the public contributors did not have a role later on in the project, seemingly



because this was the domain of experts. PC11 described the change between the start and latter stages of P1.

*“I think, we’re obviously kind of involved at the start at all the calls and the pilot workshop and going to a workshop, I felt we were involved in that. And then it has tailed off.”* PC11.

Yet, there were some discussions later in the project where a prototype public voice would have been appropriate. For example, once the public workshops were over, a steering group teleconference was cancelled and rearranged to the next day, at an earlier time. Neither PC11 nor PC12 attended. The professionals discussed the process for choosing ideas to go to the next phase of development. At one stage there had been an idea to allow the general public an input by hosting a vote on the website. But the professionals now agreed to abandon that idea. The website had not been well used. The general public were said to lack the expertise to select ideas to go forward. None of the professionals acknowledged that there was a voice missing from the discussion. Nor did anyone suggest contacting the public contributors to solicit their views.

#### **4.5.7 Legitimacy - group 3 – fresh-eyed reviewer**

The group 3 roles could be played by any motivated public contributor regardless of experience, and in any project regardless of the scope. PC22 provided a succinct summary of the fresh-eyed reviewer role that was talked about by 10 participants and played at one time or another by all six public contributors (as shown in Table 4.11 below).

*“It’s just that I am another pair of eyes in the room and I don’t come from the same background.”* PC22.

PC22 attributed their abilities at fresh-eyed review to a skill built up during many years working as an outsider.

*“ ... I spent 10 years as a consultant working on my own in massive companies and the one thing I learnt is that ... there are loads of things that nobody is going to say and half of them are thinking so I just say that thing which is what I often did at the meetings.”* PC22.

**Table 4.11 Instances of fresh-eyed reviewer.**

<b>Participant</b>	<b>Instances of observed fresh eyed review</b>
PC11	By email suggested suitable workshop venues.
PC11	At a steering group teleconference, pointed out that the first part of a leaflet was addressed to people with a condition, whereas the aim of the project was to engage with patients, carers and family members.
PC11	By email reiterated the point that the project was aiming to engage everyone, but the wording on materials was aimed at patients.
PC12	By email suggested local radio stations for advertising.
PC21	Pointed out the e-learning packages need to be highly usable to engage people.
PC21	Agreed that they had not known all the abbreviations.
PC22	Only PC22 and one professional had reviewed <u>all</u> the competing training resources prior to the review meeting.
PC22	Agreed that they had not known all the abbreviations.
PC22	Asked how NHS staff would be supported to find the time to attend training.
PC22	Asked how many NHS staff on the ground would be reached (an original aim of the project), and was persistent following up.
PC22	Asked how the professionals were going to keep in touch with 9000 people.
PC22	Said that the website was clear.
PC22	Argued against a survey as a way to get feedback.
PC22	Asked what a MOOC was (Massive Online Open Course).
PC22	Suggested shaming member organisations that had not put staff forward for training.
PC22	Pointed out that the plan to review and improve the quality improvement programme sounded like quality improvement.
PC22	Said that it was positive that people had asked to be on the training programme without being nominated.
PC22	Contributed an idea about how people should be invited to a forthcoming showcase.
PC22	Asked if it would be OK for another organisation to support a programme if the AHSN decided not to.
PC31	Asked for the numbering of papers for a meeting to be changed.
PC31	Agreed with PC32 that some web pages were easy to navigate.
PC32	Praised the clarity of an infographic.
PC32	Suggested that someone who had already had the training and was using it could speak at a training event.
PC32	Checked to make sure they understood which organisation was being discussed.
PC32	Praised a professional for leading an organisation into realising that they needed some training.
PC32	Praised some web pages and said how easy they were to navigate.

The professional participants variously explained that reviewers from outside provided a view unencumbered by the NHS organisation structures, language, culture and ways of thinking. Many professionals valued a perspective less constrained by what the budget or timescale would have allowed. A perspective not restricted by metrics could cut through a discussion or stop a meeting in its tracks and was seen by one professional (AH24) as different, but equal to, that of a hospital trust Chief Executive Officer (CEO).

PC32 explained that public contributors enjoyed a freedom not available to professionals. The public could, for example, admit to not knowing something or ask any question. Several participants described the art of asking a seemingly naïve question. PC22 described these as questions no one else in the room dared to voice. Sometimes the professionals could answer the questions, and interestingly, sometimes they could not. For PC22 not understanding prompted a question, with the exception of abbreviations. Asking what every abbreviation meant would have slowed the meetings down and wasted everyone's time. In contradiction, both NH31 and AH31 saw the explanation of abbreviations as a helpful public input, not least because many professionals did not understand them either.

This role came with a responsibility for the public contributors: to review the materials outside the meetings. PC22 reported that if they were sent materials before a meeting, they would review them. This was evident from the observations. In one notable incident only PC22 and a professional member of staff from the AHSN had reviewed all three e-learning packages under discussion. PC22 had watched the video and participated in the quizzes. When asked about this, PC22 saw it not as a validation of the public contributor role, but said,

*“How dare everyone else come along [so unprepared]” PC22.*

Fresh-eyed review could pose problems for the unwary. AH21 worried that the P2 steering group became a “*showcase*”. PC22 diagnosed further issues. If review was requested late in the process, the role became that of a “*proof reader*” (PC22). PC22 resisted merely spotting typos in what seemed to be finished material, understanding that the professionals would not make “*swathing changes*” (PC22) to websites that

were about to be launched. By the time of PC22’s interview, the P2 steering group had been dissolved. PC22 talked about the new plan, to meet with the AHSN professionals semi-regularly and provide input to their strategy.

Steering group meetings existed for AHSN member organisations to collectively ‘review and decide’ based on materials put together outside the meeting. Provided the public contributors prepared for meetings, the evidence demonstrates that every member of the public in all three projects could play this role. Humour, often self-deprecating, helped remove the sting from many of the public’s interjections. PC22, in particular, played this role to great effect but also expressed the most frustration with it. The limitation of big meetings (such as P2 and P3) is that they are not forums where detailed work gets done, hence the pattern of ‘review and decide’. In prioritising inclusivity at steering groups, the AHSN handed the public a role. The role was restricted, but only in a way that applied to all the meeting attendees from outside the AHSN, professional and public.

#### **4.5.8 Legitimacy - group 3 - patient advocate**

Ten participants talked about patient advocacy. PC31 captured the essence of the role and illustrated why public contributors did not need a relevant personal background in order to play this role.

*“ ... you don't have to have lived experience to know that patients don't want to wait too long or that they wanted to be ... treated as human beings ... ”* PC31. Only one public contributor played this role, albeit on multiple occasions. The breadth of PC32’s input is captured in Table 4.12 below.

**Table 4.12 Instances of patient advocate**

<b>Participant</b>	<b>Instances of observed patient advocacy</b>
PC32	During an update on a new programme, asked what feedback patients had given on it.
PC32	Asked whether a listening programme also included listening to patients.
PC32	Reminded professionals that elderly people do not like to be labelled as frail.
PC32	Asked whether the public understood a term being used.
PC32	During a discussion talked about the responsibility that patients and the public have.

<b>Participant</b>	<b>Instances of observed patient advocacy</b>
PC32	During an update on the development of a solution to an issue, asked if the group had involved patients.
PC32	Suggested that work including GPs also involve their PPGs.
PC32	Asked if patients understood the way two issues were connected.
PC32	From reading the papers sent before the meeting, quoted statistics that demonstrated how important it was to continue pursuing a particular programme.
PC32	Asked whether prevention training included using patient victims.
PC32	Interrogated measures and outcome statements to understand whether there was evidence that outcomes for patients were improved yet.
PC32	Asked if there was one person responsible for incident reporting and how staff knew what to do.

On the whole PC32 prompted professionals to involve patients in their work. PC32 did not directly advocate for what patients wanted or needed, although AH23 related occasions where other contributors had done this. Instead, PC32 advocated for patients to be involved so that they could speak for themselves. NH32 expressed what several professionals suggested, that public contributors could ask whether patient views had been taken into account or by asking relatively simple questions.

*“What do you think patients will think of this?”* NH32.

Whereas AH32 specifically linked patient advocacy to lived experience, PC32 spoke of patient advocacy as a role any member of the public could play,

*“You know I think any member of the public would say oh gosh you've got a decision support tool that can really highlight ... this patient is a priority, why aren't you using it?”* PC32.

PC32 said that it helped to be interested, motivated and to want to help. They promoted attending events, training sessions and reading around the subject. Observations confirmed that PC32 attended not only the P3 quarterly steering group meetings in their contract, but other quarterly P3 sub-groups. PC32 attended P3 steering group meetings having reviewed the previous minutes and ready to challenge anything not captured in the minutes. Such activity may have helped to prompt the constructive criticism and suggestions that professionals said they sought from public contributors. AH32 spoke of the reaction to PC32's interjections changing over time. At the beginning the contribution could be seen as idealistic or accusatory.

*“And I think people didn’t sort of always take to that straightaway, they probably felt like they were being, maybe not accused, but you know, sort of.”*  
AH32.

But once relationships had been fostered things improved.

*“ ... barriers have been broken down and bridges ... have been built, and people recognise [PC32] now ... ”* AH32.

#### **4.5.9 Legitimacy - group 3 - critical friend**

The term “*critical friend*” was used by both AH33 and AH22 from the AHSN but defined by neither. It is also the first item in the public contributor job description for P1 and P2, although it is not explained there either. Contributions viewed as critical friend did not fit into any other categories and extended the public voice away from merely reacting to what was put in front of them. Public contributors did not require any particular background or experience to play this role.

**Table 4.13 Instances of critical friend**

<b>Participant</b>	<b>Instances of observed critical friend</b>
PC22	Asked if a new approach was a fashion, and whether it would blow over or whether it was worth investing in?
PC22	Reinforced the size and potential of an opportunity the group was discussing.
PC22	Said that a coalition of the willing might be the best way to start something.
PC22	Asked whether the poor turnout at a steering group meeting affected whether decisions could be made.
PC32	Asked what the next steps were in a programme that seemed to be well underway.
PC32	Suggested a possible next step for the project.

PC32 seemed to sum up this role saying that if a project had the initial intention to achieve a certain set of aims, the public contributors could hold it to account by asking what had been achieved.

*“And you don't have to be an expert at anything to ask the sort of questions that hopefully would make people just sit back and think again.”* PC32

AH33 described how the contributors to P3 operated, keeping the project “*on track*” (AH33).

*“You said you were gonna do this ... and ... I haven’t heard anything about that, so what’s happening about it, and you know ... [PC32] ... would for example say, what about care homes?”* AH33.

The professionals from the AHSN talked about being challenged and asked difficult questions by the public contributors. AH21 reported that PC22 had participated in training sessions run for clinicians and provided feedback on the presentation style and the content. AH24 talked about a more fundamental question.

*“Right, okay, what are you actually trying to achieve here?”* AH24

AH23 agreed, saying that PC22 was “*firing bullets*”(AH23) and making “*the clouds part a little bit*”(AH23). AH32 talked about public contributors providing constructive criticism, motivated by wanting to improve matters. From their attendance at the P3 meetings, AH33 pointed out that public contributors challenged P3 more frequently and more helpfully than representatives from member organisations. The public contributors may have benefitted from not having the “*baggage*” (AH33) of belonging to an NHS organisation. Sometimes the public contributors could cut through acceptance that something could not be done by asking ‘but why?’ Both AH23 and AH21 thought that constructive, helpful contribution such as the critical friend role was facilitated by early involvement in the work. They noted too that PC22 often began their remarks with an apology, not that the professionals felt it was needed.

Both the term critical friend and the idea of public contributors playing a constructively challenging role seemed established within the AHSN. Staff from P2 and P3 described it. However, even though public contributors from two projects played this role, albeit on a handful of occasions, no professionals from organisations outside the AHSN spoke about it.

#### 4.5.10 Legitimacy - group 3 - keeper of the public purse

The heart of this role, which required no specific background knowledge or skills and could be played by any public contributor, was overseeing the way public money was spent, to make best use of it in the face of “*vested interests*” (PC31) in the NHS. PC31 summarised the role.

“ ... you are there to make sure that public money, not just money but ... resources in general ... are being dealt with appropriately I would say.” PC31

**Table 4.14 Instances of the public purse role**

<b>Participant</b>	<b>Instances of observed keeper of the public purse</b>
PC22	Challenged the meeting not to invent its own training programme when others, invented elsewhere, already existed.
PC22	When talking about the way P2 was marketed clarified that they did not mean something fancy or expensive, just simple things like being clear about the name of the programme and what the message was.
PC31	Pointed out that even if the NHS bought living aids for people, they would still need to be low cost.

Several other participants spoke of the size of the investment made in the NHS. But whereas PC32 joined PC31 in saying that the public was there to see how the money was spent, AH13 felt that the public’s presence helped to legitimise the amount.

#### 4.5.11 Legitimacy - group 3 - boundary questioner

PC32 in particular urged the professionals to share and work more across boundaries.

“*[The] NHS never really changes in terms of how things develop in silos and they're...slow to share and push things forward.*” PC32

**Table 4.15 Instances of the boundary questioner role**

<b>Participant</b>	<b>Instances of observed boundary questioner</b>
PC31	Asked why GPs from their local council area were not signed up to an initiative.
PC32	Asked whether a local community care organisation could share their approach with primary care providers.
PC32	Asked whether all the community services organisations had signed up to an initiative and if the remaining ones were being chased.
PC32	Asked whether an organisation could share their learning and outcome measures for their training programme.



<b>Participant</b>	<b>Instances of observed boundary questioner</b>
PC32	Cheered silently (noticed by everyone around the table) when a representative from a community organisation said that they have care home staff signed up to their training.
PC32	Suggested that including care homes into community programmes might be easier once the CCGs start commissioning them.
PC32	Checked whether an online system was common to all AHSNs in the country and whether there would be sharing of ideas.
PC32	Talked about a whole systems approach to Medicine Safety rather than just having sign up from the acute trusts.
PC32	Asked about links between P3 and another AHSN project.
PC32	Suggested that Fire and Rescue had a framework for safe and well visits and this might generate ideas for how to involve other agencies.
PC32	Suggested asking one of the other regional AHSNs which had done a lot of work on care homes.
PC32	Asked about tagging the P3 training onto training that was already going on to the target audience.
PC32	Contributed to a discussion on how to engage outside organisations in training and suggested various levers and motivations for getting them involved.
PC32	Suggested inviting a speaker from an out-of-area acute trust that had dramatically reduced falls to a falls prevention event.
PC32	Asked whether other AHSNs were looking at insulin management, and whether there was an opportunity to share learning.

Although only two public contributors played this role, PC32 played it extensively. This reflected both PC32's active role in the P3 steering group meetings, and their involvement in two other sets of sub-project meetings.

#### **4.6 Functional variables - leadership**

The data collected in this section shows how the experience of PPI at the AHSN was affected by leadership practices within the programme. Through leadership practices the professionals managed the tensions between involving the public contributors and achieving the organisation's objectives, in partnership with their member organisations and within constraints such as time and budget.

##### **4.6.1 Leadership - responsibility for PPI**

The data evidencing the tension between one individual being responsible for PPI and everyone in a team feeling that it is part of their job became apparent at two different levels: centrally and within the projects. AH14, the PPI manager, summed

up the debate surrounding whether PPI should be a single, centralised job or a responsibility shared by all the managers.

*“And at the moment there's a trend ... saying we shouldn't separate our PPI it should be underpinning everything ... If you don't have it as a separate work stream or somewhere as a separate category it gets forgotten about.” AH14*

Other priorities might squeeze out PPI if a group of managers shared responsibility for it. And good practice might not be developed and disseminated. AH14 reported saving the AHSN from having to *“learn by trial and error”* (AH14). The downside of a centralised PPI role is the possibility that project team members do not feel that involving the public is anything to do with them. Potentially a gap could exist between a centralised PPI function that sets up the involvement and the working of PPI in the individual projects.

Identifying responsibility for involving the public provides interesting comparisons between projects. Most participants named AH14 as the person responsible for involving the public. Participants described AH14 matching projects with contributors, setting them off, checking in occasionally and reviewing success with the professionals. Once matched with a public contributor, each project took a different approach to involving them. In P1 multiple participants specifically said their responsibilities did not include involving the public. For example SE11 said they were not responsible for *“drawing them in necessarily”* (SE11). AH11 acknowledged that the public had not been as involved as they might have been, but that they did always receive important communications. Although both public contributors and two of the AHSN staff saw AH13 as having taken a lead within P1, AH13 themselves named only AH14.

In P2, AH22 described a member of their team (AH21) as being jointly responsible for leading PPI in the project with AH14 and PC22. AH21 described being responsible for involving PC22. Both PC22 and AH21 recounted a set of events, one-to-one telephone updates and a meeting over coffee that all occurred outside of the official, quarterly steering group meetings.

In P3, AH33 described being responsible for securing engagement from all kinds of stakeholders, including member organisations and public contributors. Where direct reports managed a sub-project, they took responsibility for communicating with both members and public contributors. Although this distributed responsibility led to effective communication and contact (both PC31 and PC32 reported receiving the paper in advance of meetings), it may have confused the public contributors. PC32 named only AH14 as being responsible for involving the public. PC31 named a very senior AHSN manager, at that time an AHSN staff member who ran a sub-project and then confided that they found the AHSN structure very confusing.

#### **4.6.2 Leadership - getting the job done**

One aspect of leading involvement is managing the tension of including other parties while trying to deliver a project. Hence making time for public involvement, even when the schedule is short, takes significant leadership. Evidence collected from P1 demonstrated the impact of speed on the aspiration to involve the public. AH13, who managed P1, recognised the leadership challenge.

*“I think it is a trade-off ... I think a part of that is to do with the willingness of those who are involved to work at the speed that the AHSN wants to work at.”*  
AH13

AH13 described the approach required to deliver the project despite the tight schedule.

*“ ... there’s a limit to how ... you can slow the bus down to ... make sure you get the best of that input and you know we just didn’t have time to ... so I really had to, in some cases, make decisions and say this is what’s going to happen ... but I did try ... you know to have a discussion, give other people opportunities to say I don’t think this is a good idea ... ”* AH13

Both PC11 also noticed the problems with the speed described here by PC12.

*“I think the barriers were just the time and ... the place of where things were, you know.”* PC12

PC11 related providing feedback on the colours of the project logo for the marketing materials. At the next weekly teleconference AH13 thanked everyone for their input, but explained that the materials had had to go to the printer in a rush. So despite the feedback, a decision had been made to stick to the existing AHSN colours. PC12 regretted that the pace of the project had not allowed public involvement in the selection of the final design. In fact, PC12 would have liked their local condition group to have been able to vote on the short list.

Neither P2 nor P3 suffered from P1's tight schedule. However, evidence from both suggests that there was still a tension between getting the job done and involving the public. AH22 noted that their update calls with AH21 tapered off, and guessed this was because the team became very busy. NH21 noted the conflict between focusing on the task at hand, and being open to other input.

*“ ... we often have a job to do and if we're taken off track with ... something that somebody else wants to talk about ... it's not helping to get the job done.”* NH21

One participant, NH32, said that bigger meetings worked best as a vehicle to involve the public because they were facilitated. The facilitation kept all attendees on task, and prevented any individual pushing their own agenda. The evidence from participants, then, is that speed and workload could erode involvement, even where it began with the best intentions. The P1 team did not find a way of mitigating the impact of the tight timeline on their efforts to involve their public contributors. Although the informal contact in P2 between AH21 and PC22 waned, the regular, formal, facilitated meetings established a minimum, protected schedule for public contribution.

#### **4.6.3 Leadership - teleconferences**

Tasked with getting work done at speed and a geographically dispersed team, P1 alone opted for teleconferences. These offered a route to improved inclusion, although with potential costs in other areas. Neither PC11 nor PC12 could have attended face-to-face meetings during the day. Teleconferences held over lunchtime were the only way to involve these working public contributors. In a negotiation

facilitated by AH14, the P1 team changed their meeting schedule to accommodate the public contributors, a move appreciated by both PC11 and PC12.

*“And then they were pretty flexible and I liked that. So they worked around me as well, you know.”* PC12

A range of email communication accompanied the teleconferences. Both public contributors praised the way they were kept in touch via frequent emails. Email requests for their opinion could be dealt with flexibly, in their own time.

*“Yes, we got emails about that, yes. So that was good.”* PC11

The use of teleconferences for the weekly meetings was not without difficulties. PC12 explained missing the first one in an email, waiting to be rung rather than using the dial-in number. AH13, who ran P1, described chairing teleconferences as *“stressful”* (AH13).

*“Yeah if something does get lost because you often don't know who said, who made the point, I mean unless you do it in a very rigid way or say it's [AH13] speaking now, my point is ... ”* AH13

AH13's difficulties chairing the calls were reflected in PC11's experience. PC11 described difficulty butting in on the conversation, feeling as if their input would waste time, and that the conversation had moved on before the opportunity came to interject. Some of these difficulties appear to be associated with teleconferences as a medium.

*“It's also hard, it's hard enough anyway thinking that what you are going to say ... is of any importance ... I found it a lot easier, when we had the initial meeting and then when we ... I found that a lot easier to be able to come in and say anything and actually ... make any sort of impact, yeah.”* PC11

Some of the difficulties reported by PC11 could have been associated with the particular teleconference provision at the AHSN. Background observation notes recorded at the time reveal the low quality of the calls, characterised by indistinct voices, buzzing noises, and hearing without being heard. Participants frequently hung up and dialled-in again in the hope of improving the audio quality.

However, some of the difficulties appeared to be associated with characteristics particular to P1. Not only was the project as a whole on a tight schedule, each teleconference felt rushed. This limited the potential for contribution. PC11 found the absence of advance agendas troublesome. In addition, PC11 reported that their presence at the teleconferences may not have been known to the other attendees.

*“...you dialled in and they've already started, no one knew you were there ... And then I think one or two of the calls, I don't think anyone knew I was actually there until the very end when I said, oh, bye.”* PC11

Out of the 11 teleconferences attended by the researcher between 18<sup>th</sup> May and 27<sup>th</sup> June 2015, PC11 and PC12 both attended only one. PC11 attended a further one teleconference, and emailed apologies for missing three more. PC12 did not raise any issues connected with teleconferences, although limited attendance may explain this. PC11's testimony, however, suggests that they may have been a silent and unrecorded presence at some of the remaining calls.

On two occasions teleconferences were rearranged at a time outside the lunch hour, meaning that the public contributors were unlikely to have been able to attend. This pattern suggested, despite the initial flexibility the P1 team showed, later scheduling did not accommodate the public contributors. On another occasion, when neither public contributor joined the call, AH13 wondered if the meeting should wait for them, but as no one had heard from either PC11 or PC12, the teleconference went ahead. By contrast, when AHSN members could not make a planned briefing call, AH13 arranged times to speak to them individually.

Unlike the chairs of P2 and P3, AH13 did not chair any differently when meetings included public contributors. AH13 described PC11 and PC12 as professionals, capable of *“interacting at the level we needed”* (AH13) and who therefore did not need to be treated differently. Rather, AH13 reported that teleconferences posed equal difficulties for all participants.

*“ ... but people have got to be quite assertive I think in teleconferences, it's very easy to sit there and not say very much ... ”* AH13.

At the end of a call, AH13 asked the meeting generally if anyone had anything to add, rather than asking each individual in turn. One formality AH13 did observe as chair was asking attendees to introduce themselves at the start of the call.

#### **4.6.4 Leadership - *ad hoc* face-to-face meetings**

As well as the teleconferences, P1 held two face-to-face meetings. The public contributors talked about the first one, the pilot workshop, when they, other public contributors, and AHSN staff participated in a dry run of the workshops that were to be offered to the general public. AH13 and AH14 welcomed the public contributors, moving forward to greet them, making introductions, and offering refreshments.

*“I think when I was there [they] approached me firstly and made me feel like part of the group.” PC12*

SE11 ran all the workshops for the general public. At the pilot, attendees had the opportunity to introduce themselves, speak about health experiences, and take part in the same way that the general public would. This provided the P1 team with a dry run to check the timing, running order, and logistics. During the small group discussions SE11, and SE12 actively drew each individual into generating design ideas. Despite being prompted twice by AHSN staff, SE11 asked for feedback on the process and content of the pilot only as an aside, almost as lunch was served. This timing effectively limited the potential to critique the pilot.

The second P1 face-to-face meeting reviewed the final three selected concepts to agree on the next steps. The public contributors were not invited. An email signalling the final teleconference thanked PC11 and PC12 and closed down their involvement the week before the meeting. However, one portion of this meeting involved a discussion on the project report, including how much of it to make public and which parts the public might be interested in. PC11 and PC12 could have contributed to this. No one raised this point or suggested getting in touch with them.

#### 4.6.5 Leadership - large face-to-face meetings

P2 and P3 both opted for large, quarterly meetings open to both public contributors and members. These meetings focused on reviewing progress made outside the meetings, rather than on getting a job done. The leadership challenge then was in establishing a space for public contribution in the midst of large, formal, infrequent meetings. For P2 as a whole this *modus operandi* seemed to have worked less than perfectly as the steering group was dissolved after three quarterly meetings. PC22, AH22 and AH21 all spoke of a plan to continue working together by meeting monthly as a small group with a focus on strategic plans. Certainly PC22 reported feeling that “...a formal meeting with an agenda and 20 people” (PC22) did not play to their strengths. The AHSN staff and PC22 all hoped to improve the nature and value of the public contribution in the future.

Both interview and observation data revealed leadership practices associated with involving public contributors in formal review meetings. Both NH21 and NH22 (the P2 chair) realised that having public contributors in the room was only a start, the public needed to feel comfortable and build relationships with the professionals. NH22 reported chairing meetings involving the public differently, making eye contact and inviting contribution. NH22 spoke of the chair’s responsibilities to promote discussion of the updates, and to ensure that all the voices around the table were heard.

*“...the risk of course is that the ... public representatives ... they may’ve been well chosen, they may’ve been well briefed, they may be perfectly comfortable in their roles but if they don’t see an opportunity to contribute at all or they aren’t invited to it at all then they are only tokenistic ... even if they’re there on absolutely the best, the best grounds and the best intentions.” NH22.*

The chair began P2 meetings in a couple of noteworthy ways. First, they introduced themselves using only their first name, and without their job title, although none of the other professionals followed suit. Second, they looked around the table and asked if anyone wanted to add anything to the published agenda. During the meetings, the chair responded, supported and reinforced PC22’s contributions. In NH22’s absence, AH22 chaired a P2 meeting in a similar vein. To close meetings, both AH22 and NH22 made eye contact with each individual when asking for Any



Other Business (AOB). NH22 went further at the end of the first-ever steering group, asking how the meeting had felt and looking first to the public contributors for feedback.

P3 meetings, with 25 or more attendees, risked overwhelming public contributors. AH33 noted the challenge of managing big, formal meetings filled with clinicians when many patients find it hard to speak to their own doctor. The leadership challenge was getting contributions from everyone around the table, not just the public. To P3's credit, both PC31 and PC32 reported feeling comfortable. PC31 said,

*“I think on the whole most of the people on that Board [P3] and who I came into contact with went out of their way to try and make you feel not intimidated.”*  
PC31

Before the meetings, PC32 reported invariably receiving the papers in advance via email. AH14 periodically attended the P3 meetings and would catch up with PC32 beforehand. At the beginning of the meetings, each person introduced themselves using their full name, job role and organisation. During the meetings, PC32 described finding the professionals ready to explain whenever asked. AH31 described a professional who asked for explanations of things they already understood when they could see others were lost. Observations showed professionals twice teaching PC32 about new evidence or programmes. NH31 recounted consciously chairing to make sure the patient and public voices were heard. PC32 said that the chair turned to the public contributors specifically at points to ask if they wished to contribute.

*“And also I found in the meetings themselves, whoever chairs it is quite often very good about specifically turning to either [PC31] or I and asking if we've got anything that we either wish to bring up or comment on or. So it's inclusive, you're not made to feel as though you're an add-on they have to do.”* PC32

Observation showed that the chair sometimes turned first to the public contributors to invite comment. The chair used self-deprecating humour to good effect and backed up a point made by PC31, telling the AHSN that its response needed to be firmer, and tabling an action to escalate further.

Even with good leadership practices, some participants suggested that large quarterly meetings still limited public involvement and needed to be supplemented. NH32 talked about involvement in more intimate settings, about using first names, and about developing human relationships. AH24 felt that the attitude and openness of NHS staff was decisive in making involvement work. NH21 wondered whether public contributors would benefit from a chance to discuss board papers with the chair before the meeting. NH31 described discussions about giving the public contributors on P3 a specific slot on the agenda. NH22 pondered asking professionals to introduce themselves by describing their experience as users of health services. AH21 recommended regular communications and contact outside the scheduled meetings. PC32 talked about attending more than just the quarterly meetings.

*“I can't see what you can give if you don't know what the ... organisation is doing somehow ... I think you need to be more involved in some way, that's my personal opinion ... ”* PC32

An opportunity for further involvement came when PC32 was asked to make a presentation on the patient perspective at a workshop.

*“So I did a presentation on that and then that was it, I was involved then in the work that was taken forward.”* PC32

#### **4.7 Functional variables - power**

The functional variables showed that the experience of PPI within each project could be quite different, even though each operated within a common structure at the AHSN. The imbalance, exercise or sharing of power between professionals and the public within each project held the possibility of shaping the experience of PPI for the participants. This section sets out the data collected in respect of power within each project, and also highlights the way that power could be exercised by individuals or organisations not present at meetings.

#### 4.7.1 Power - P1

The evidence from all the P1 participants suggests that PC11 and PC12 could steer aspects of the project, but within relatively narrow bounds. The P1 team implemented the project. But the project board, on which PC11 and PC12 did not sit, made the key decisions on budget and timescale. The AHSN invited PC11 and PC12 to contribute only to the implementation of P1, and not to its conception or management. Thus it is no surprise that PC11 felt they had no influence over decisions, since the project structure limited their contribution to implementation.

*“I don't think really I had any influence on decisions.”* PC11

There were limits to the power of the professionals, as well as the public. AH13, a relatively new staff member, expressed uncertainty about the bounds of their authority despite belonging to the project board as well as P1.

*“I wasn't clear at the outset of this whether I was deciding how to do this or not, or whether or not I did have to defer back the whole time ... because I was relatively new to the organisation ... I thought well I don't kind of go right out on a limb and do something that's not wanted, so I did defer back the whole time ...”* AH13

On the other hand, AH13 reported that interacting with AHSN members by telephone obscured status indications such as attire or job title and so tended to equalise power relations.

At the teleconferences, PC11 appeared to find it hard to interject when the other attendees seemed to be in the middle of a discussion they had started beforehand.

*“When ... those ... last few phone calls before the workshops, you ... felt that things being discussed were things that had already been disc ... You know, that were ongoing and hadn't been part of the other project ...”* PC11.

The conversations between the P1 team and the public contributors, facilitated by AH14, gave PC11 and PC12 power over the scheduling of the teleconferences. But during the teleconferences, the public contributors affected only minor operational details. The experience reported by PC12 illustrates this point. PC12 felt that their

local knowledge informed the timing and location of their closest workshop. However, PC12 did not influence the selection or development of the chosen designs. Indeed, PC12 felt unable to lobby for their preferred design selection method, a survey of local people. The project provided no route for PC12 to press for the solutions their local condition support group badly needed, either in this phase of the project or in future phases. The P1 team did find another way to share some power, though. The AHSN staff introduced PC12 to a team working directly with PC12's condition. PC12 reported that this team had stayed in touch, providing the opportunity to connect into local programmes aimed at their condition.

#### **4.7.2 Power - P2**

The public contributors in P2 operated under similar conditions as those in P1. However, rather than being part of the implementation team, the public contributors formed part of the steering group, where decisions were made to approve or change particular programmes that had been planned by AHSN staff to AH22's vision. Bigger decisions were also referred to the AHSN's board. Leadership practices in P2 meetings shared power with the public contributors multiple times during each meeting. NH22 appeared to share power deliberately and knowingly.

*"... there could be ... ways of ... actually ... shifting the power I think."* NH22

In addition, NH22 recognised that the power sharing may not have gone far enough.

*"... when you repeat that back to me ... even that can sound paternalistic you know we must ensure involvement ... so I wonder if there are ways ... of breaking the mould or introducing new approaches without disrupting the necessary governance of ... a board."* NH22

PC22 could call on a wide range of roles when invited to speak. This range, their experience from other organisations, preparation for meetings, and attending events outside the core meetings all allowed PC22 to exercise their voice when called upon. Occasionally, this process worked in reverse. PC22 described making contributions that AH22 agreed with, and which enabled AH22 to push ideas through.

*“ ... so my role which I assume is why [AH22] likes me being there is because sometimes I say things that [they] think yes that would be my ethos, yes that would be what I would do ... so I end up giving [them] a little bit of ... leverage.”*  
PC22

Both the public contributors and the AHSN staff operated under conditions of constrained power. Senior staff had more control, for example the decision to dissolve the P2 meetings after a year appeared to come from AH22. PC22 reported that they had not been consulted. Even though the AHSN staff from P2 had tried to develop materials with PC22, AH22 felt their approach had fallen short of co-production. AH22 described co-production as never *“just with one person”* (AH22) and therefore P2’s work with just PC22 could not be called co-production. AH22 explained their view of the revolutionary history of co-production.

*“ ... it came ... from the Civil Rights Movement in the U.S ... it, it was about changing the balance of power ... and for me, co-production ... if you’re working with somebody on a one-to-one basis, it’s great, it, you can do an awful lot of work together, but it doesn’t feel like it’s a collective community of thought.”*  
AH22

Even though professionals in P2 acknowledged the possibility of a change in the balance of power through PPI, the constraints remained. Within these constraints, leadership activity could momentarily share power with PC22. PC22’s legitimacy, based on the roles played, could share power back in the other direction, back to AH22.

Outside of the P2 steering group meetings, PC22 discovered the limits to the power in the AHSN’s invitation to be involved. PC22 described a bid to bring the public contributors together, without any AHSN staff present.

*“We had a big meeting, loads of presentations, everyone spending their time and in that, that’s when ... we said could we have a meeting with just the public contributors so we could try and work out what we all think we are doing.”* PC22

PC22 reported that a senior AHSN manager supported the idea of the public contributors working together.

*“ ... and [a senior AHSN manager] said it was a great idea and all that.”* PC22.

After a delay, the AHSN staff did arrange for the public contributors to meet, although AHSN staff attended part of the meeting too.

*“ ... so then they eventually arranged that meeting for October ... and I had chased it ... So anyway eventually we had the meeting in October and ... [AHSN staff] came along ... and [they] disappeared off.” PC22*

PC22 reported that six public contributors came to this meeting. The six agreed to meet again, to encourage the rest of the public contributors to come along, and to meet in a different local city. When the AHSN staff returned, the public contributors reported their agreements and requested a Doodle Poll to sort out dates, and the complete set of email addresses for all 12 AHSN public contributors. None of the requested support transpired. In its place, an email conveyed the decision not to go ahead.

*“So I got no email addresses, I got no Doodle Poll, I got no meeting, I got no nothing. So then I emailed [them] and said can I please have the email addresses so I can send out the whatever and would you like me to send out the Doodle Poll and [they] said ... about a week later ... [PC22] we ... have decided not to do that” PC22.*

The limits of the invitation to contribute at the AHSN became clear in this incident.

*“ ... you can't say to people this is what we'd like to do and then they go, get back in your box now and just close the lid, don't pop out again ... ” PC22*

According to PC22 the AHSN responded to say that another meeting of public contributors would be convened, but that AHSN staff would attend. PC22 corresponded with another public contributor, but chose not to pursue the issue any further with the AHSN.

*“ ... you're saying I can't have a meeting and I can't discuss these things whatever. And it just seemed really like well this is really, it's completely disempowering, it's unprofessional ... if you did that to a patient group how would that be?” PC22*

The experience coloured PC22's view of involvement.

*“I told my [family member] and I am like so [name] you see it is just lip service because the minute we all said actually we'd like to get together and we'd like to decide how we get on.” PC22*

PC22 carried on contributing because of the relationships they had built with AH21 and 22.

#### **4.7.3 Power - P3**

Like P2, P3 involved public contributors in the decision-making forum, rather than the implementation team. Like P2, P3 meetings contained multiple moments of leadership activity that shared power with PC31 and PC32. PC32 recognised these moments of power sharing.

*“Yeah no I haven't been told to button my lip or anything.” PC32*

AH33 echoed PC32's sentiments, saying that public contributors had a freedom to speak up, but needed to have power shared in order to exercise their voice amongst senior professionals.

*“I guess it's just ... making sure that ... they are helped if they need to be helped in how to express themselves yeah.” AH33*

In a further demonstration that the public contributors did possess power, a number of P3 participants described escalation routes outside the meetings: through AH14, the public contributors on the AHSN board, and the meeting chair. PC32 said,

*“But I mean we've only got to pick up the phone or send [AH14] an email, and I know that but [AH14]'d be ... you know.” PC32*

PC32 used the meeting process to exercise voice, and ensure it was recorded. PC32 pointed out an omission in the minutes and actions from a previous meeting and was backed up by the chair.

*PC32: “Top of page 6, please, where ... right at the very top, where it talks about the ... ensuring practice managers and practice nurses are involved. I think I did say at the last meeting that it would be good to see ... the PPGs in there – Patient Participation Groups – specifically mentioned, if that's okay?”*

AH33: “*Yeah.*”

NH31: “*Can you add that as an action?*”

Excerpt from a P3 meeting.

Despite the moments of power sharing throughout each meeting, PC31 said, “*No not really I don’t think*” (PC31) when asked if there had been any opportunity to influence decision-making. Perhaps PC31 recognised the difference between the power to speak up during the meetings, and the ability to challenge the constraints to public contributor power. On the other hand, neither public contributor listed decisions they would have liked to influence, but could not. It is also worth noting that public contributors had a seat at meetings where some professionals did not. AH31 did not attend the P3 steering group meetings, but organised some of the sub-projects. In another example, AH14 facilitated the attendance of public contributors at the AHSN board, despite not being a member of that board. PC32 provided an example of a public contributor sharing power back with professionals, by using the legitimacy of the voice of the public to support the uptake of a system the AHSN were driving.

#### **4.7.4 Power *in absentia***

All three projects demonstrated a power differential between public contributors and professionals in regard to power *in absentia*. Public contributors needed to be present in order to exercise power. Examples from each project illustrate the point. In P1, PC11 and PC12 needed to be present in order to ensure that meetings were scheduled at times they could be available. Multiple *ad hoc* meetings and teleconferences were held outside of lunchtimes. In one instance, the meeting was scheduled even while AH13 acknowledged that PC11 and PC12 were probably unable to make it.

AH13: “*I suppose ... I mean I can’t imagine [PC11] and [PC12] will be available but, anyway, if we, if we set it up at a particular time we can tell people ...*”

Excerpt from a P1 teleconference

In the public contributors’ absence, no one either defended their ideas, or sought clarification of them outside the meeting. The P1 team removed PC12’s suggested survey questions after a short debate.



SE11: *The next question, we can get rid of that.*”

AH12: *“Yeah.”*

AH13: *“Well that was, that was, that was the suggestion from [PC12] actually, [PC12].”*

Excerpt from a P1 teleconference

In contrast, meetings and telephone calls were explicitly arranged so that professionals could attend. If they did not, then the AHSN called them individually. The treatment of the AHSN members provided further evidence. When various members could not make the teleconference to refine 12 ideas down to three, AHSN staff arranged additional calls to obtain their feedback.

In P2 and P3, the professionals projected power *in absentia* by sending deputies to the meetings. While this might have been an imperfect projection of power, the option was not open to public contributors.

AH21: *“Err, [PC21], a PPI Rep with [PC22], I’ve not heard from [them]. I’d assumed [they were] coming, but [aren’t].”*

Excerpt from a P2 meeting.

## **4.8 Functional variables - trust**

Trust is a variable that reveals what the experience of the PPI programme at the AHSN was like. Few participants mentioned trust explicitly. The observational data suggested that this was not because trust was absent, but because it was not an issue. Not only was distrust seemingly absent, but other factors suggest the largely unremarked presence of trust. Examples included the range and extent of the contributions, the new roles played by the public contributors, and the predominantly positive tone of the feedback the participants gave at interview. This section is presented in two parts. The first offers the evidence that the public trusted the professionals. The second part describes the evidence that the professionals trusted the public contributors.

### **4.8.1 Trust in the professionals**

None of the data collected indicated that the public contributors distrusted the professionals or their organisations. A number of the professionals suggested that

they had given thought to building trust in the minds of the public contributors, for example “ ... *you do need the atmosphere of trust and openness ...* ” (AH14). Part of the answer to this seemed to be for the professionals to be trusting and open themselves.

*“ ... if I'm inhibited by the closedness ... that I'm sensing round me then we're not going to get public members to, to feel open either.”* AH14.

AH14 took this point further, indicating that professionals should make themselves “*vulnerable*” (AH14). The most obvious example came from the P1 pilot workshop. AHSN staff attended along with public contributors, and all participated as if they were members of the general public with a health condition. Of the four AHSN staff present, three (AH14, AH13 and AH12) contributed to the pilot workshop on the basis of personal or family health conditions. For the AHSN staff, this meant speaking about personal matters in front of work colleagues. AH14 linked this open and vulnerable contribution to establishing an atmosphere of trust for involvement to take place in.

*“ ... it's also stepping out of their comfort zone because to involve the public and to be fair you actually have to be open and transparent yourself ... you can't expect the public to talk openly about their experiences ... when you're there not sharing anything yourself...”* AH14

For other professionals, openness was achieved just by the presence of public contributors.

*“So I think there's a, there's a slightly more measured pace and not a formality it's a ... it's a kind of openness ... ”* NH22

NH22 attributed the improved openness to the feeling of being observed when public contributors attended.

*“ ... the consciousness among the NHS officers that they are in some ways under observation, that it, it works as an antidote to any kind of ... clan dynamic.”*  
NH22

Two professionals worried about factors that may have reduced trust: the size of the P3 meetings (NH32) and a level of bureaucracy over small things such as expense claims (AH23). On the whole though, the data seem to indicate public contributor trust of the professionals as an operating condition of PPI at the AHSN, rather than trust as something being built, eroded and then rebuilt.

#### **4.8.2 Trust in the public contributors**

PC11 indicated that they felt trusted.

*“But I was always made, it was never ... Always made to feel trusted, I guess. No one badgered me about anything, trusted that I read it ... ”* PC11

AH32 explained that the public contributors helped to establish a trusting atmosphere in which the professionals would feel comfortable sharing mistakes. The public contributors could affect this atmosphere by introducing themselves thoughtfully.

*“ ... [PC32] does introduce [themselves] as public contributor and this is why I'm here ... to sort of set people's minds at ease ... ”* AH32

AH32 indicated that once the professionals trusted the public contributors to be constructive, rather than just critical, then the meetings became more open and honest.

*“I think it needs to be constructive ... there's no point just standing there and saying your service doesn't work ... You need to say why it doesn't work or ... ”* AH32

PC32 established this trust, according to AH32, by acknowledging the context of mistakes, and also by praising what went well.

*“At the community forum, when someone presented from [county] Care Services, [PC32] then turned round and said I like that, that's a good thing”* AH32

Although data collection took place over a year, no differences emerged in terms of the nature or form of contributions over time and no other participants reported this

change other than AH32. However, PC32 had been attending P3 meetings for a year beforehand, so it is possible that the contribution changed during this first year.

By contrast, AH32 talked about an incident, which seemed to reduce trust in a public contributor. At a P3 meeting, one public contributor complained about the way the board papers were presented, finding them hard to follow. The chair had also jumped about between agenda items, adding to the confusion. However, AH32 interpreted the complaint as one directed against a member of the AHSN staff who had put the board papers together for the first time.

*“ ... there was a comment made about the presentation of the papers... Which could easily have been taken aside and done outside, and maybe, I think it was the only thing that was said all meeting ... And it was a criticism of a new PA ... Which I thought was very poorly managed ... ”* AH32

Even while acknowledging that the public contributor had not intended their remarks to be personal, AH32 seemed to feel that this incident had undermined trust that the public contributors would behave according to unwritten rules about good meeting behaviour. NH21 reinforced this point. Public contributors needed to time their lived experience stories appropriately, when relevant to the item under discussion. Public contributors also needed to understand when professionals were bound by government directive, making further discussion a waste of time. Finally, professionals needed to be able to trust the public contributors not to go off at a tangent, but to stay on topic so as to help the professionals to get the job done.

The trust in the public contributors may be surprising in one respect. One participant thought the growth of rules in the English NHS was reducing trust between staff members.

*“ ... one of the things that I think is missing in ... the NHS at the moment is trust in our colleagues.”* NH21

The tick box approach to PPI provided an example of this lack of trust.

*“ ... I think we are in danger of making it a science when it should be a humanitarian thing, a thing that's collaborative rather than a tick box exercise.”*

*It is ... but again it takes me back to the word trust ... people are so risk averse at the moment.” NH21*

Although NH21 felt that the requirement for public contributions (the tick box) reflected the lack of trust in NHS staff, this feeling did not appear to affect the trust the professionals displayed towards the public contributors in any of the three projects. Other than the one incident AH32 described, none of the observations contained evidence of public contributors behaving in ways likely to undermine trust. All of the public contributors respected and participated in the meeting processes laid down by the AHSN. In this sense, the public contributors justified the trust the professionals showed in them. All the participants understood and abided by the unwritten rules governing meeting behaviour. In part, this may be attributed to the recruitment and matching process run by AH14 who attempted to assign public contributors to projects appropriate to their skill set.

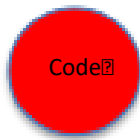
#### **4.9 Extent of the involvement**

A network map for each project shows the extent of public involvement achieved. The maps show the number and strength of the connections between the public contributors and their professional counterparts and thus the extent of the involvement. Highly involved public contributors should have multiple, strong links with the professionals. This section starts with the key to the network maps, and then presents the map for each project in turn. The focus throughout is on understanding how involved the public contributors really were in the work of each project.

##### **4.9.1 Key to the network maps**

The key shown in Figure 4.1 applies to all three network maps. It shows the meaning of each symbol. Strong connections are those where two individuals named each other as connections (shown as a connecting line with an arrow at both ends). Weak connections are those where one individual named another, but was not named in return.

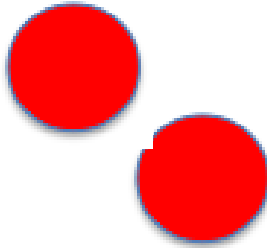
**Figure 4.1 Key to the network maps**



Each circle represents an individual. Their participant code identifies them.



Circles of the same colour are individuals from the same organisation.



Circles further up and to the left of a network map are individuals further up in the organisational hierarchy.



Double headed arrows connect those individuals who named each other as people with whom they had meaningful discussions about the project.

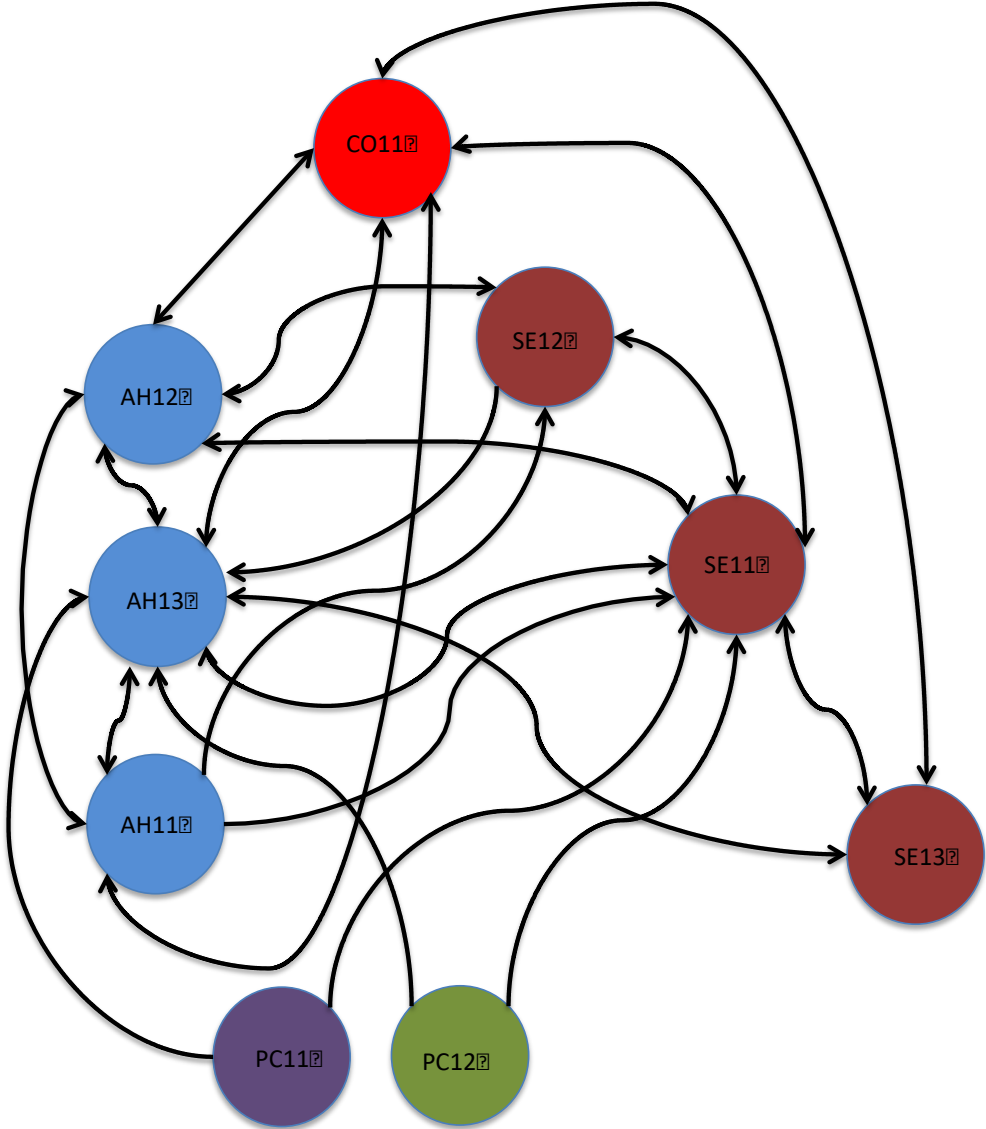


Single headed arrows go towards a person named as someone with whom an individual had meaningful discussion, but who did not also name that individual.

#### **4.9.2 Network maps**

Each map shows only the connections between participants in this research. Other connections are summarised in the accompanying text. Limiting the connections simplified the network maps. Limiting the connections to those between participants meant that each connection in the maps had the potential to be strong (that is, two way). Limiting the connections also focused the analysis onto the relationships between the professionals and the public in the projects, and thus demonstrated how involved the public contributors became in each project.

**Figure 4.2 Network map for P1**



Because P1 had a small project team, everyone participated in the network survey. Figure 4.2 shows the connections the team members listed. Excluded from this map are the connections the professionals listed with staff from their own and the other organisations (the AHSN, SE and CO) but who were not part of the project team. The public contributors also listed connections that have been excluded from the map. PC12 reported having meaningful conversations about the project with their condition support group and with family members. PC11 listed AH14 as a connection. As AH14 did not form part of the P1 project team, and therefore did not take part in the network survey, this connection has been excluded from Figure 4.2.

The network maps show the context in which the public contributors have formed connections. Figure 4.2 shows the professionals in P1 as each having multiple, strong connections with each other. This means the professionals were in touch with each other outside the weekly teleconferences. By contrast, the public contributors had only weak connections to the professionals. Both PC11 and PC12 listed AH13 and SE11 as people with whom they had had meaningful conversations. Neither AH13 nor SE11 listed PC11 or PC12. The public contributors each had only two, weak connections in a project characterised by multiple, strong connections between the professionals. It is hard to escape the conclusion that PC11 and PC12 were not extensively involved in P1. In fact, the SNA data corroborates PC11's statement that some teleconferences seemed to be continuations of conversations the professionals were already having. Whereas PC11 described their meaningful conversations with AH13 and SE11 as occasional, many of the connections between professionals were described as occurring daily during the period the teleconferences were being held.



Figure 4.3 Network map for P2

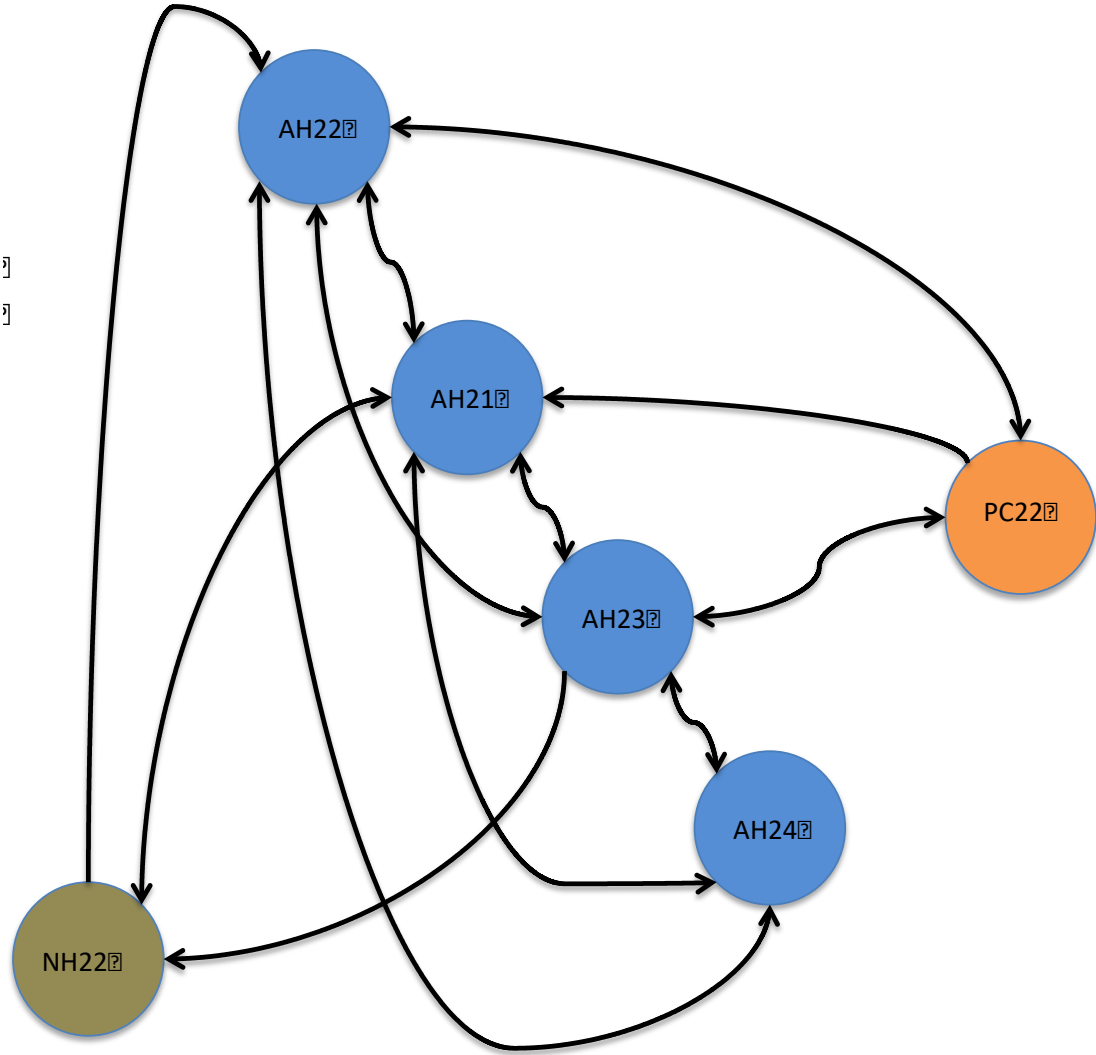
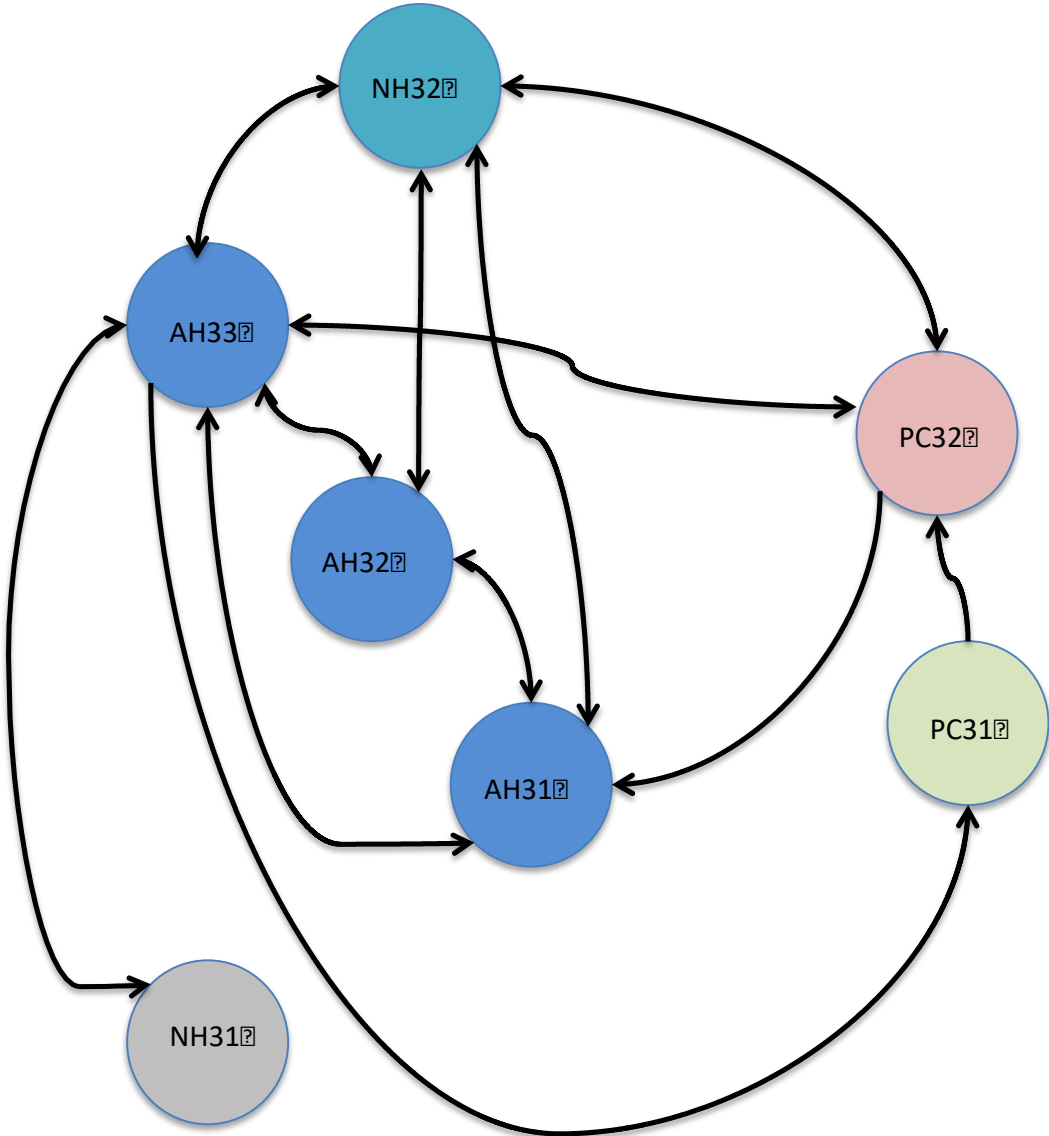


Figure 4.3 shows the network survey map drawn from six of the eight participants in P2. PC21 was not interviewed. NH21 was interviewed but did not answer the network survey questions. Excluded from this map are connections listed by the professionals: colleagues, superiors, member-organisation representatives, and external organisations. However, all of PC22’s connections are listed as they were all P2 participants.

The striking thing about Figure 4.3 is the balance. PC22 is connected in a broadly comparable way with the professionals. PC22 listed and was listed by AH23 and AH22. In addition, PC22 listed AH21. In comparison with P1, PC22 appears to be effectively involved. Digging further into the comparison between connections, PC22’s links with AH21, AH22 and AH23 were approximated to be six, four and

two times in total across the project so far. By contrast, AH21, 22 and 23 described their links with each other as being at least weekly. This further detail reveals the involvement to have been more extensive than that in P1, but considerably less frequent than for project team colleagues from within the same organisation.

**Figure 4.4 Network map for P3.**



In P3, connections including colleagues, supervisors, member representatives and external organisations were excluded from Figure 4.4. PC31 listed the two public contributors on the AHSN board as connections, as well as the ones shown in Figure 4.4. All of PC32’s listed connections are shown as they were all P3 participants.

Figure 4.4 shows a difference between the two public contributors in P3. PC31 had no strong connections with any professional. PC31 had one weak connection, with AH33, who listed PC31, but PC31 did not reciprocate. This may reflect PC31's confusion over the structure and governance of both P3 and the AHSN. PC32, by contrast, shows two strong, reciprocated connections (with AH33 and NH32) and one weak connection with a professional (AH31). Broadly, PC31 seems as extensively involved as PC11 and PC12, but less extensively involved than PC22 and PC32. Like PC22, PC32's connections with the professionals were more occasional (every two or three months) than the professionals' connections with each other (which tended to be daily, weekly or at least monthly).

PC31 listed PC32 as a connection but this link was not reciprocated. PC32 explained the absence of a link with their fellow public contributor on P3, saying

*“ ... but there wasn't anything for me, I don't think, contentious enough where I felt I needed somebody else to back me up.”* PC32

#### **4.10 Effects variable - value**

The structural variables presented the evidence for the rules and guidelines governing the PPI programme at the AHSN. The functional variables set out the evidence showing how the PPI programme operated day-to-day. This final section presents the evidence for the effects variable, value, which shows changes that were directly attributable to public contributors. The focus in this section is on triangulated evidence of effects directly attributable to public contributors. The triangulation is from multiple participants recognising the same effect, or from different forms of data (interview, observation, or documentation) demonstrating the same effect. Evidence of the value of public contribution is laid out from each project in turn.

##### **4.10.1 Value – P1**

The professionals in P1 overwhelmingly cited PC11 and PC12's contributions to the pilot workshop as their most valuable contributions. Some of the value (ascribed by SE11, SE12 and AH12) proved to be for PC11 and PC12's engagement in

workshops as members of the public. However, P1 did provide several instances of triangulated data demonstrating effects from public involvement. As recalled by several participants, PC11 proposed changes to the workshop format.

*“It spent too long individually saying who we were and what our story was. Then everything was too rushed, actually once, what things you were going to design.”*  
PC11

Audio recordings at the subsequent workshops showed that SE11 and SE12 asked participants to introduce themselves to the other people sitting on their table, instead of to everyone else in the room. This change kept the introductions shorter, and extended the time to work with participants on producing design ideas, exactly as PC11 had suggested. Although the effect on the ultimate outcome is unknown, this change helped P1 to focus workshop time on the primary aim of generating ideas from the general public.

PC11 also affected the wording used in the P1 promotional materials. The initial materials failed to capture the intent to be open to everyone, not just people suffering with a condition.

*“It was for carers as well, not just patients. And they went, oh yes, sorry. So then they changed to are you or someone you care for.”* PC11

After PC11’s input at a teleconference, the tag line used in all the materials changed from: -

“Are you living with a challenging health condition?”

to: -

“Are you or someone you know living with a challenging health condition?”

After reviewing the draft poster, PC11 emailed to say that some of the wording still focused exclusively on patients, that advertising the refreshments might draw in a bigger audience, and that how to attend could be clearer. Comparing the draft with the final poster shows the effect of PC11’s comments.

Draft poster wording: -

“3 ways to share your ideas for a product that could improve your quality of life and maximise independence” and “Anyone can attend, please register on our website.”

Final poster wording: -

“Share your ideas and experience with us in a number of ways during June and July” and “Visit our website, call or email us to attend our workshops to share your ideas” with the following addition “Refreshments & food provided at workshops.”

While the changes made to the poster can be traced directly to PC11’s comments, the difference to public understanding, or to workshop attendance, cannot be assessed. But PC11 clearly compared the wording with P1’s stated aims and made suggestions calculated to improve the likelihood of achieving them, that is, of keeping the programme open to everyone, and of attracting the biggest possible audience.

PC11 and PC12 recalled some effects that remain unverified. PC11 thought they made the original suggestion to produce a news item, rather than just advertising. A spot did run on the local news, but no other participants, transcripts, notes or documents confirmed the attribution of the original idea. PC12 said they changed the professionals’ views of what a layperson with a condition was, although none of the professionals mentioned this. One effect, recalled by PC12, was impossible to verify, given the scope of this research. PC12 reported raising an issue at the pilot workshop on behalf of a fellow member of a condition support group who was pleased that the idea was now “*out there*” (PC12). PC12 was the only public contributor who saw themselves as a conduit to and from a community.

#### **4.10.2 Value – P2**

In P2, PC22 downplayed the value of their involvement.

*“I don't feel really involved particularly, I don't feel pivotal and I don't really think I've changed more than about 5%, not even that, 3% ... ” PC22*

It is worth noting that PC22's feelings about their role and its value contrasted with the views of the professionals from P2. One experienced professional, who attended both P2 and P3 meetings, described PC22's contribution in the following ways.

*“I think that [PC22] is an absolute breath of fresh air, I love the different angles that [PC22] brings ... because [PC22] makes it not about the NHS.” NH21*

AH21, AH22, and AH24 also spoke warmly of PC22's involvement, and there is evidence to support their view. Both PC22 and AH21 spoke of a period before the start of the P2 steering group meetings when PC22 attended and critiqued training events hosted by AH21. AH21 recalled responding to PC22's feedback both by changing what did not work and continuing to use what did. Both PC22 and AH21 also agreed on the effect PC22 had on one of the AHSN's annual conferences. As well as persuading the professionals to switch a jar of sweets to a jar of fortune cookies and reducing the length of an exercise, PC22 ran one of the stalls when someone else dropped out. The ultimate outcome of these changes is unknown but, for example, in using fortune cookies PC22 helped the AHSN to provide refreshments more consistent with the public health message on reducing sugar consumption.

From PC22's observed contributions at the P2 steering group meetings, though, two key instances stand out. In the first instance, the AHSN staff had brought three different training packages for review by the P2 steering group. Besides AH23, PC22 alone had reviewed all three packages and thus provided an effective critique for each. Along with a telling interjection from PC21, who asked the AHSN to compare the three packages using the same criteria, PC22 used questions that helped the AHSN staff to realise that they had proposed a solution without a full definition of the problem. The subsequent meeting minutes contained actions on the AHSN staff to refine their approach and bring the proposed training solutions back to a future steering group. AH23 recalled the incident thus.

*“ ... so particularly with the education pathway we took, we took along the proposal ... we went, ‘This is what we think’s gonna work guys’, and ... you know the good contributors came back and went ‘It seems like you’ve found a solution before you know what your problem is, why are you doing that?’ ... So we had to go ... back to the drawing board and try again ... ” AH23*

The evidence showed the interjections PC21 and PC22 made during the discussion of these training packages, and the response of the AHSN. However, the difference to the programme from proceeding with a more thought-through approach was impossible to value.

In the second instance, AH22 asked the steering group for ideas. A local hospital trust, undertaking a quality improvement project using an approach supported by the AHSN, planned a workshop to disseminate the learning. AH22 and the hospital favoured a small event to permit detailed coverage, and asked the P2 steering group how the audience should be selected. PC22 suggested that the AHSN ask potential audience members to say why they should be there and what they would get out of it.

*PC22: “ ... rather than you pick, the great [AHSN] ... ask people to say why they think they should, and make it like a reward almost: so, ‘Why would you want to come on’ ... ‘How do you think it might benefit what you’re doing at the moment?’ and see who pitches the best case, because that show a bit of commitment from them, as well... ”*

Excerpt from a P2 steering group meeting.

AH22 liked the idea immediately and sought agreement from around the table to propose this approach to the hospital. This instance is a clear example of the AHSN committing to take a public contributor’s idea forward. Unfortunately, at the time of interview, AH22 did not know whether the idea had been used by the local hospital.

*“The [local hospital] are ... organising that, and ... they’ve taken that on board, they’re gonna think about why people should be there ... ” AH22*

The limits of public contribution to an AHSN became clear in this example. When the AHSN adopted an idea, but relied on persuading member organisations to implement the idea, then it might not have been put into practice.

#### 4.10.3 Value – P3

In P3, PC31 could not point to any difference as a result of public contribution.

*“I have said I don’t see, I don’t think we contribute that much really to be honest ... Or I haven’t really, I found it very interesting, but I’m not sure I’ve added any value in one sense ... ”* PC31

PC31 made few interjections to the P3 meetings during the data collection period. The most potentially valuable contribution, concerned why their local area had not joined a particular AHSN forum. The chair supported PC31, saying that the time to rely purely on collaboration had passed. PC31 volunteered to raise the issue with a patient leader.

NH31: *“And being nice and collaborative and supportive clearly has got to be to a point. We might need to have a different conversation ... ”*

PC31: *“I could contact the ... one of their Patient Leaders to ... and suggest they ask ... ”*

NH31: *“And force it through that route?”*

PC31: *“Yeah.”*

NH31: *“Great idea.”*

AH33: *“Thanks, [PC31].”*

Excerpt from P3 meeting.

At the time of interview, PC31 had not raised the issue.

*“I haven’t fed ... that back yet either, I must admit, because all the things that, where I could feed it back on ... the last one I couldn’t go to and the next one ... isn’t until September, although I could email [name] I s’pose.”* PC31

The minutes from this P3 meeting recorded an action on AH33 and AH32 to pursue the matter further with the CCG. It is possible then, that this interjection of PC31’s will have an effect in the future, beyond the data collection period.

PC32 made multiple contributions in each observed P3 meeting, attended quarterly sub-project meetings, and again made multiple contributions. However, there are few verifiable opportunities to trace value from these contributions. As AH32 explained, representatives from member organisations attended and then decided what to work on.



*“ ... I think [PC32] has some very valid points that people take away and implement ... obviously we don't know everything that people implement ... ”*  
AH32

The AHSN had decided to extend PC32's contract beyond the two-year term, confirming the positive views AH32, AH33 and NH31 gave at interview. However, all the participants struggled to find verifiable examples of change attributable to PC32. AH33 came closest, saying that PC32's focus on care homes kept them on the agenda and reduced the 'siloed' (AH33) working in the NHS. In some ways, PC32's value is hard to discern because their aims were so well aligned with P3, and so often served to reinforce the AHSN's direction of travel. For example, AH33 described PC32's agitation to include GPs in P3's work. Although the AHSN would have liked to include them, they had found it difficult. A working group, including PC32 but which pre-dated the data collection for this research, developed an approach, and the first meeting had been held. PC32 reported having missed this meeting, but had been disappointed to learn that none of the GPs had brought representatives from their PPGs along. PC32 clearly intended to keep pushing. For the AHSN, then, PC32 was an additional meeting attendee with a voice advocating cross-organisational working and collaboration. In other words, PC32 made frequent interjections offering real support for the AHSN in furthering the objectives set for them by government.

The extension to the two-year term meant that PC32 would be able to continue cajoling the AHSN and its members to work across organisational boundaries that, as AH33 hinted, stand in the way of seamless patient care.

*“So and I guess you know, the public contributor is seeing it not just from the point of view of that episode of care ... it's more of that impact on a person's life.”* AH33

PC32 described two further examples of value that were impossible to verify. After a P3 meeting, AHSN staff had credited PC32 with turning the tide of opinion and persuading organisations to sign up to a new programme. PC32 also described contributing, along with PC31, to a workshop presentation prepared by a clinician on the P3 team and aimed at members of the public.

A number of professionals in P3 reported value from the public contribution that seems important but impossible to trace. AH32, NH31 and NH32 (from P3) and NH22 (from P2) all reported differences in the tone and content of the meeting involving the public contributors.

*“ ... making people think and be more clear about what it is they are trying to describe, trying to avoid jargon but more importantly it is taking on the views that those patients and carers share with us, about what is important.”* NH31

The adaptation of leadership activity as a result of public contribution, however, is one meeting change for which there is triangulated evidence. While no comparison data exists, the chairs of both P2 and P3 reported consciously changing the way they managed meetings. Numerous observations pointed to deliberate attempts to draw the public contributors into the discussion. Examples included specific invitations to add items of any other business, and making eye contact after update presentations to allow the public contributors to comment first. In further confirmation, the chair of the P1 teleconferences did not adapt their style, resulting in a demonstrably reduced opportunity for the public contributors to speak up.

The final word on value from the research participants comes from the chair of P2, who observed that what the AHSN had done for its members was to model a particular approach to PPI.

*“I think that the model, the model that we are using in the AHSN is a good example of a particular model.”* NH22

#### **4.11 Conclusion**

The conceptual framework, constructed from the literature review (see Chapter 2, **Error! Reference source not found.**), has guided the research questions, the propositions, the coding, the analysis and the presentation of the findings. This logical linkage between the questions and the findings assists in providing answers to the overall research question, *what is the nature of PPI in inter-organisational health networks, and how is it valued?* The structural variables, functional variables and the network maps provide evidence of the nature of PPI. The structural variables describe the rules, guidelines and practices. The functional variables show

how PPI operated. The network maps demonstrate the extent to which the public contributors were involved in the work of the projects. Finally the effects of the public contribution demonstrate its value. The next chapter presents how the findings affect the debates in the literature, and the theoretical propositions.

## 5 Discussion

### 5.1 Introduction

This chapter presents a discussion of the findings detailed above, highlighting the contribution this research makes to the academic debates in PPI and IONs. The chapter presents the discussion following the conceptual framework (see Figure 2.10 **Error! Reference source not found.**). The nature of the context provided for PPI by the ION is considered before turning to the structural variables, the functional variables, the extent of the involvement and finally the evidence of value. The propositions related to each section of the conceptual framework are reconsidered in the light of the data and supported, refuted or refined. The changes to the propositions then necessitate adjustments to the conceptual framework.

### 5.2 The ION as context for PPI

The first element of the conceptual framework is the ION, comprising AHSN member organisations, as the wide context for the PPI programme. The findings show that this wide context was actually made up of multiple IONs. The identification of other networks that must be added to the conceptualisation of the context supports the view that the search for whole networks is illusory (Charbonneau and Bidart, 2011). Networks overlap. Their boundaries are fuzzy. A case study, on the other hand, requires sharp delineation of the scope (Yin, 2014). This means that case studies of networks must carefully follow Conway and Steward's (1998) advice to define the inclusion criteria, even where the network under study is considered to be an organisational form rather than a unit of analysis.

While the conceptual framework acknowledges the influence of the wider ION context on the PPI programme at the AHSN, it provides no detail as to the nature of this influence. The findings show some of the specific ways in which the context of multiple IONs shaped the PPI programme. The biggest beneficial influence from belonging to the network of NHS organisations in England, for example, seems to have been over trust. PPI at the AHSN exhibited at least a minimum level of trust

because, following Das and Teng (1998), the study consisted of functioning project teams. Despite this, there was no evidence of the expected cycles of trust building (Huxham and Vangen, 2005). Given that trust need not start from zero (Lewicki, Tomlinson and Gillespie, 2006), the presence of minimum trust must be accounted for in another way. One factor that seems to account for trust that predates an actual relationship is perception (Popp *et al.*, 2014). However, the AHSN was a relatively young organisation and it was unknown to the public contributors in advance of their recruitment. So the perception of trust could not have existed about the AHSN specifically. The conclusion drawn is that a minimum level of trust in the AHSN as part of the network of English NHS organisations represented a starting condition for the PPI programme. The implication is that organisations outside the NHS might not be able to draw on this trust and so might have to spend more time in a continual cycle of trust building.

There were some instances where membership of the network of NHS organisations in England seems to have constrained the PPI programme and increased the workload. For example, some professionals described the effort and the compromises necessary to begin a dialogue with other parts of the NHS. Similarly, HMRC rules on the distinction between public contributors and consultants seemed to have constrained the ways in which the AHSN defined and used public contributors. The PPI-specific network also constrained involvement at the AHSN. The pursuit of both shared strategy and consistent implementation among members reigned in the desire of some AHSN professionals to be radical and to lead PPI from the front.

The shape of the network of AHSN member organisations acted as a further constraint on the PPI programme. The diverse membership and geographic dispersal of member organisations forced the AHSN's projects to choose between working in large, infrequent face-to-face meetings and more frequent teleconferences. Thus the shape of the ION limited the diversity of involvement mechanisms that the AHSN could adopt. This limitation did not exclude some perfect involvement mechanism that would otherwise have been available (see Rowe and Frewer, 2005, for an attempt to identify ideal involvement mechanisms), but shows that the AHSN chose from a limited range of options. The context of multiple IONs thus benefited and

constrained the PPI programme at the AHSN. The preceding paragraphs show that the AHSN could not freely choose aspects of the involvement. The limits to this choice show that the influence of multiple IONs can be seen as part of the standing conditions of power for the PPI programme. Clegg's model (reproduced in Figure 2.11) shows the standing conditions as governing causal power in the first circuit, that is, episodic, observable interactions.

The AHSN itself provided the immediate context for the PPI programme in the conceptual framework. While much of the PPI literature observed that PPI is context-dependent (Evans *et al.*, 2014; Staley, 2009), the attempts to capture that context did not draw on existing typologies in other literatures. For example, in categorising context Oliver *et al.* (2008) reported on broad-brush categories such as country location, and institution type. Unsurprisingly, the context described at this level did not explain the success of the involvement. Institutions of the same type, for example health institutions, can be organised along very different lines. By contrast, the business and management literature contained tightly specified organisation types. Hence the ION literature allows the AHSN to be classified as a mandated NAO (Provan and Kenis, 2008) and lays the groundwork for generalisations from the findings at this AHSN to other mandated NAOs.

The immediate context can be further categorised following Ferlie *et al.* (2009). This mandated NAO had formal links with its member organisations, was complex due to the number and heterogeneity of members, and was funded. Two categories proved difficult to apply here. The extent to which the funding was munificent, and the extent to which shared values operated between the network members. Munificence could be judged comparatively in a multi-case study, but not in a single case such as this one. Finally, the extent of shared values in this study was not a classification category, rather the subject of in-depth study through the exploration of different aims and objectives, and of diversity within the projects.

In order to add refinement to the classification of the mandated NAO, the lifecycle model could be used (Popp *et al.*, 2014). However, assigning the precise lifecycle stage appears to be easier in retrospect, after a network has ceased to operate. While the "formation" stage (Popp *et al.*, 2014, p. 57) is over, the AHSN could be placed

in any of the “development and growth” (Popp *et al.*, 2014, p. 61), “maturity, sustainability and resilience” (Popp *et al.*, 2014, p. 69) or “death and transformation” (Popp *et al.*, 2014, p. 71) stages. As an NAO towards the end of its initial licence period, facing renewal under terms that are likely to be amended (AHSN network, 2017), the AHSN could not be clearly placed in one lifecycle stage. While appealing as a typology, the lifecycle model is of limited use.

The immediate context for PPI here is thus a mandated NAO with formal links to members, a complex operating environment, funding and which is beyond the formation stage of the lifecycle. This categorisation allows exploration of the first proposition, if the PPI programme benefits from the NAO form of the health network, then there will be evidence of staff deploying some or all of: negotiation, boundary spanning, teaching, coaching and mentoring skills. The evidence from the literature was mixed. Ferlie *et al.* (2009) found that network managers did adapt their behaviour, but also detected both successful and marginal PPI in these networks, suggesting that the behaviour change was not decisive for successful PPI. On the other hand, Ferlie *et al.* (2009) did not discover much evidence of PPI at all in the eight networks they studied so the results might be different in a network organisation with a focus on PPI. Mandated NAOs were considered by the ION literature to be the network organisation form that was closest to a more traditional hierarchical entity (Popp *et al.*, 2014). Thus in NAOs the behaviours associated with network managers might not be much in evidence.

The findings show that AHSN professionals did display the soft skills anticipated in a network organisation. They worked at finding roles for their organisation that added value to their members through negotiation, boundary spanning, coaching and mentoring. The extent of this labour represented practice at using the soft, influencing skills that Ferlie *et al.* (2009) found amongst managers in health networks. This case study reinforces Ferlie *et al.*'s (2009) findings that network managers exhibited network-based soft skills. However, further review must determine whether the professionals deployed these soft skills in their dealings with the public contributors. The next paragraphs consider the evidence for each soft skill and its application to PPI.

Negotiation between the professionals and the public contributors occurred at the start of the involvement (for example, over scheduling project meetings). The PPI manager often mediated these negotiations. After the projects started, though, little negotiation occurred about the process, role or success of the involvement. Only in one project did the professionals and the public contributor have a mid-term dialogue about the involvement, and this discussion was prompted by the project's failure to attract widespread attendance from members at its quarterly meetings. The resulting dialogue brought about an agreement with the public contributor to meet regularly, in a smaller group, and to have discussions focused on strategy rather than implementation.

Boundary spanning behaviours directed at the public contributors were neither observed nor reported at interview. For example, none of the professionals attended groups, organisations or settings the public contributors were part of. Teaching (instruction given by one to many) occurred once, when the public contributors attended an induction meeting. This teaching took place towards the beginning of the public involvement programme and was mediated by the PPI programme manager. There were limited instances of coaching (instruction given one to one), and here feedback is regarded as an instance of coaching. In one project, professionals twice took the opportunity to explain new information to the public contributors. While the professionals thanked the public contributors, only one reported an instance of specific feedback. Furthermore, the professionals did not go on to develop a dialogue about the skills or opportunities for further high value interjections. In addition, the one instance where a public contributor was perceived to have acted in an inappropriate way was not followed up with any attempt to provide coaching on meeting etiquette. The only other reported incident of coaching did not come from a professional at all. In fact, it came when a public contributor coached a professional rather than the other way round. None of the participants spoke of any mentoring (a formal one-to-one relationship that may include coaching) at all.

The importance of soft skills, and especially coaching through feedback is reported in the PPI literature as connected to public contributor confidence, motivation and ultimately to improved contributions (Evans *et al.*, 2013; Crocker *et al.*, 2016). The



limited instances of coaching, in particular, appear to be a missed opportunity for a PPI programme at an NAO. Given the evidence here, it is not surprising that some participants in Crocker *et al.*'s (2016) study suggested that public contributors should ask the professionals for feedback, rather than waiting for it. This would be one way for public contributors to initiate a dialogue part way through their involvement activities.

Proposition 1.1 stated, if the PPI programme benefits from the NAO form of a health organisation then there will be evidence of staff deploying some or all of: negotiation, boundary spanning, teaching, coaching and mentoring skills. Soft skills tended to be deployed at the beginning of the involvement projects, rather than used to maintain a dialogue with the public contributors throughout. In fact, this study found more evidence of the soft skills being directed at the network members rather than the public contributors. The mandated form of the NAO allowed staff to develop and deploy soft skills, but required those skills to be directed at member organisations. The public contributors appeared to be squeezed out by the primary constituency, the member organisations.

### **5.3 Structural variables**

The structural variables capture an organisation's intent with regard to its PPI programme in the form of policies and practices. While the structural variables have some similarity to the "architecture of PPI" factors (Brett *et al.*, 2009, p. 48), the conceptual framework here applies beyond research and allows for levels of context outside the immediate organisation. Furthermore, the architectural factors mix structural and functional variables together. The distinction made here allows the exploration of the organisational intent and the way that intent is carried through or not.

Most of the structural variables were positively associated with effective PPI reflecting the AHSNs commitment to adopting best practice PPI. However, there were exceptions: the initiation of the overall PPI programme and the projects by the organisation, the management of the programme by a professional, the lack of diversity amongst the public contributors, and the narrow scope of the projects.

Given the AHSN's objectives in collaboration, unmet health needs and health equality (see Section 1.4), the lack of diversity amongst public contributors appears surprising. After all, Staley (2009) drew a connection between diversity and benefits to marginalised communities in health research. The selection of public contributors based on white-collar backgrounds, or indeed any set other set of skills, excluded people who did not have, or were not prepared to develop those skills (Barnes *et al.*, 2003).

However, the AHSN recruited public contributors specifically to join advisory and steering groups and selected individuals with the strategic skills necessary to help move projects forward. The public contributors' white-collar backgrounds added to the range of roles they played. These roles came not at the expense of a lived experience role, but in addition to it. Some of the value attributed to PPI in the findings arose as a direct result of the public contributors' occupational backgrounds. Finally, the findings revealed that the NHS professionals by and large trusted the AHSN's public contributors to behave according to the unwritten rules governing effective meetings. The network collaboration literature revealed the diversity dilemma that is apparent here. Collaborations require enough diversity to make working together worthwhile, but not so much as to remove the ability to work together (Popp *et al.*, 2014). Through its selection of public contributors with white-collar backgrounds the AHSN improved the likelihood of constructive meetings while limiting the possibility that involvement might have an impact on marginalised communities.

NAOs such as the AHSN are seen in the ION literature as close to single organisation hierarchies (Popp *et al.*, 2014), relying on traditional forms of authority. The exceptions to best practice found here appear to be associated with preserving the NAO's authority. Instead of ceding power to a diverse group of public contributors by co-producing the PPI programme, the AHSN held power close. The structural variables formed those parts of Clegg's (1989) standing conditions of power that are determined by the organisation (rather than its network context). In Fraser's (1990) terms, the structural variables ensured that the PPI programme held the public contributors as a "weak public" (Fraser, 1990, p. 75) because their role did not encompass decision-making.

The findings revealed some missing structural variables. The speed of a project, the involvement experience of the professionals, the presence of outside parties, the number of publics, the frequency of involvement, and its duration, all appeared important to the participants. All should be added to give a more complete picture of the makeup of PPI. Thus the set of structural variables provided a good start for capturing the organisational intent of the PPI programme, but were incomplete. Proposition 2.1 has therefore been amended to, the structural variables can be used to describe the organisational intent of PPI in an inter-organisational health network with the additions of: speed, professional experience, external parties, the number of publics, the frequency of involvement, and the duration of the involvement.

**5.4 Proposition 2.2, the structural variables do not affect the effectiveness of PPI in an inter-organisational health network, has been refuted by the data. The structural variables form the organisation-determined elements of the standing conditions of power for a PPI programme. As such, the structural variables partly determine the extent of public contributor power in the way the involvement functions by determining the overall scope of the organisation's involvement: initiating and leading the programme, or coming along when invited. The structural variables thus capture the organisation's intent with regard to the PPI programme in way that permits PPI programmes to be compared across organisations. The structural variables allow researchers to understand how much power the organisation has ceded over the standing conditions of power. Functional variables**

The purpose of the functional variables is to explore how a PPI programme works in practice. The organisational intent is captured in the structural variables. The day-to-day interactions between the professionals and public contributors may deliver this intent or subvert it. The experience of PPI in any project could be quite different depending on the aims and objectives of the participants, the legitimacy of the public contributors, the leadership practices, the specific power relations and the extent of trust. These are explored in turn in the sections below.

## **5.5 Functional variables - aims and objectives**

Wilson *et al.* (2015) saw aligned aims as enabling effective PPI. The ION literature, on the other hand, referred to a goals paradox (Popp *et al.*, 2014) where collaboration is worthwhile only if parties' aims are diverse enough, but effective only if the aims are similar enough. Further, individuals, organisations and absent parties may all hold different aims and objectives for a collaboration (Huxham and Vangen, 2005). Thus while the PPI literature might prompt organisations to select public contributors who share their aims and objectives, the ION literature suggested that diversity is inevitable and, within limits, potentially fruitful.

The findings revealed that the public contributors brought a diverse set of aims and objectives to the AHSN's project work. As expected by the ION literature, so did the other parties to the projects. While none of the three projects conducted an exercise to flush out all of the aims and objectives (as suggested by Huxham and Vangen, 2005), the findings showed that holding a dialogue about aims and objectives was worthwhile. Where the public contributors stated a specific area of interest, the AHSN could attempt to match them with a relevant project. Note, the matching here was not based on identical aims and objectives, but on those that were similar enough. Even where the public contributors were not matched to a project that chimed with their aims and objectives, the dialogue resulted in introductions to other teams and other projects. Thus the AHSN held out the possibility that the public contributors' aims and objectives might be met through future involvement. Where the project matched the contributors' aims but not their objectives, maintaining a dialogue about those objectives allowed the AHSN the potential to respond to them over the medium term. These findings, then, suggest that public contributors should establish and maintain a dialogue about their aims and objectives. Those not met in the short term could be addressed in the future.

## **5.6 Functional variables - legitimacy**

One of the ways the ION literature illuminated the study of PPI was in the understanding that, in a network, all the parties to a collaboration faced a legitimacy challenge. In this study the mandated NAO worked to establish its own role with member organisations. Within the NAO, the professionals faced multiple, shifting

roles. This context both helped and hindered public involvement. The openness to adapted, flexible roles may account for a broader base of legitimacy and thus the range of roles discovered in this study. Of course, the need to negotiate with a broad range of other stakeholders also constrained the AHSN in its provision of a space for PPI, to the frustration of some professionals.

The PPI literature contained limited consideration of involvement from the viewpoint of the professionals. One of the strengths of this study was the inclusion of interview data from both public contributors and professionals. The NAO form of the AHSN meant that many professionals were not only clinical managerial hybrids (Ferlie *et al.*, 2013) holding multiple jobs, but were also working outside of any of these job descriptions, and making further adjustments such as working over lunchtimes, evenings and weekends as a result of the PPI programme. Another change to the professionals' roles appeared to be the pressure to share personal health stories in groups including not only the public but also colleagues, some of whom were more senior. The PPI manager at the AHSN identified the need for professionals to make themselves vulnerable and linked it to building an atmosphere of trust. Mayer, Davis and Schoorman (1995) identified trust as a requirement for a collaboration where the parties are taking a risk. However, as professionals may not enter an involvement programme voluntarily it seems unreasonable to expect them to take a personal risk.

The range of roles played by the public contributors in this study reinforces and extends results from elsewhere. Martin (2008) found that public contributors drew on knowledge and skills from their life experience, including their occupation. Martin saw this as conferring legitimacy by extending the public's claim to representativeness by using the knowledge and skills to speak for a wider public. More recently, a study published since the data collection for this thesis ended found public contributors playing a range of roles. Crocker *et al.* (2016) interviewed 38 public contributors to health research projects about their impact. The authors conceptualised six different roles that they called "mechanisms of impact" (Crocker *et al.*, 2016, p. 4). In common with this study, the authors said that the roles "frequently overlap, and PPI contributors may embody all of them at different times throughout the life of a research project" (Crocker *et al.*, 2016, p. 7).

Three of Crocker *et al.*'s roles map onto the roles identified in this thesis. Their "expert in lived experience" (Crocker et al., 2016, p. 5) is similar to the lived experience role except it is defined purely in terms of contribution to research proposals. Their "creative outsider" and "free challenger" (Crocker *et al.*, 2016, p. 5) roles combine aspects of the fresh-eyed reviewer and critical friend roles. Three of Crocker *et al.*'s roles did not appear in the findings of this thesis: "the motivator", "the bridger" and "the passive presence" (Crocker *et al.*, 2016, pp. 5-6). While none of the professionals in this study spoke of increased motivation from involvement, one public contributor could conceivably have been playing the bridger role, albeit in the opposite direction, when producing leaflets for an external group. Similarly, one professional reported something akin to the passive presence role when they claimed that public contributors made meetings more open.

The three additional roles from Crocker *et al.* (2016) can all be placed into groups 1 and 3 of the typology established in Table 4.3 and are shown in italics in Table 5.1.

**Table 5.1 Adding roles to the groups**

<b>Group 1 Roles determined by the background and experiences of the public contributor</b>	<b>Group 2 Roles determined by the nature of the work the public contributor is involved in</b>	<b>Group 3 Roles any motivated public contributor can play in any involvement work</b>
Lived experience	Prototype public	Fresh-eyed reviewer
Occupational knowledge		Patient advocate
Occupational skills		Critical friend
<i>Bridger</i>		Keeper of the public purse
		Boundary questioner
		<i>Motivator</i>
		<i>Passive presence</i>

Crocker *et al.* (2016) saw the main implications of their findings on the range of roles as improving perceptions of the value of PPI. The authors suggested that professionals assess which of these roles are important at the start of a project and recruit public contributors accordingly. However, this advice seems to miss the opportunity to empower public contributors. At the AHSN, no public contributor played all the roles available to them, representing a lost opportunity. Thus public contributor knowledge and understanding of the range of roles and how to play

them appears to be of at least equal importance to encouraging professionals to use expanded understanding of the roles for recruitment.

Despite the range of roles reported here, the findings also capture widespread uncertainty among public contributors about their roles. Crocker *et al.* (2016) reported that only a small proportion of their public contributors had expressed this same uncertainty. Perhaps this is linked to the proportion of public contributors who play the lived experience role (34 out of the 38 participants in Crocker *et al.* (2016) were patients or carers or both). Despite the prevalence and widespread understanding of this role, the PPI literature reported issues with its perceived legitimacy among professionals. Some professionals appear not to believe in the value of lived experience (Pollard and Evans, 2013). Even when they believed in its value, some professionals believed lived experience was only legitimate if the public contributors were also representative of (Li *et al.*, 2015) or at least very in touch with a patient group (Wilson *et al.*, 2015). The roles in Table 5.1 have the potential to give public contributors additional sources of legitimacy, not by improving their representativeness as suggested by Martin (2008), but by providing additional bases on which to make a contribution.

Table 5.1 offers public contributors the ammunition to refute another view reported amongst some professionals. Thompson *et al.* (2012) found that professionals considered experienced, trained, and otherwise professionalised public contributors less credible, authentic and legitimate. However, in Table 5.1, only one out of the 12 roles relies on the public contributor as a naïve or “pure” (Braun and Schultz, 2010, p. 408) member of the public. Only when playing the prototype public role might public contributors need to recall a time before their exposure to the language and culture of the NHS. Other roles, such as fresh-eyed reviewer demand only that the public contributor be an outsider to the involving organisation.

The range of roles shown in Table 5.1 may assist with understanding ‘patient leaders’. Several sources outside the academic literature, namely Lucy Watts (2016) and Gilbert and Doughty (2012), have promoted patient leadership. The key idea was that patients should come to the table as equals with professionals and have a voice at all levels of decision-making in the NHS. The government has expressed a

similar aspiration (Department of Health, 2012). However, like the strategic work at the AHSN, direct lived experience becomes less and less relevant to decision-making at higher levels of the NHS. The range of roles in Table 5.1 could give aspiring patient leaders a way to understand the basis of a contribution that does not depend on lived experience.

While Crocker *et al.* (2016) described the public contributor roles as mechanisms for impact, they did not elaborate on how these mechanisms might work. Neither did the authors link the roles into any form of theory or conceptual framework to help understand why the roles might be important or how they lead to impact. The following paragraphs present the facilitators and barriers to maximising the number of roles the public contributors can play, considering each group in turn. Figure 5.1 shows the way a public contributor's potential to play a group 1 role flows into the actual observation of that role being played. Beginning on the left-hand side of Figure 5.1, some factors may prevent a public contributor from playing a group 1 role. First, if the public contributor does not have the relevant background (for example, lived experience of a condition as a patient or carer) then the contributor cannot play that role. If the public contributor does not recognise the role then they cannot play that role. Finally, even if the public contributor has the background, and recognises the role they may reject that role (for example, they may not identify themselves as a patient). Even where a public contributor has the background, recognises and accepts the role, the public contributor may not actually play that role. If professionals do not recognise the role, or if the role is already being played by a professional, then the public contributor potential to play a group 1 role may not be realised. Figure 5.1, then, starts to capture why public contributors did not play all the roles they were qualified for.

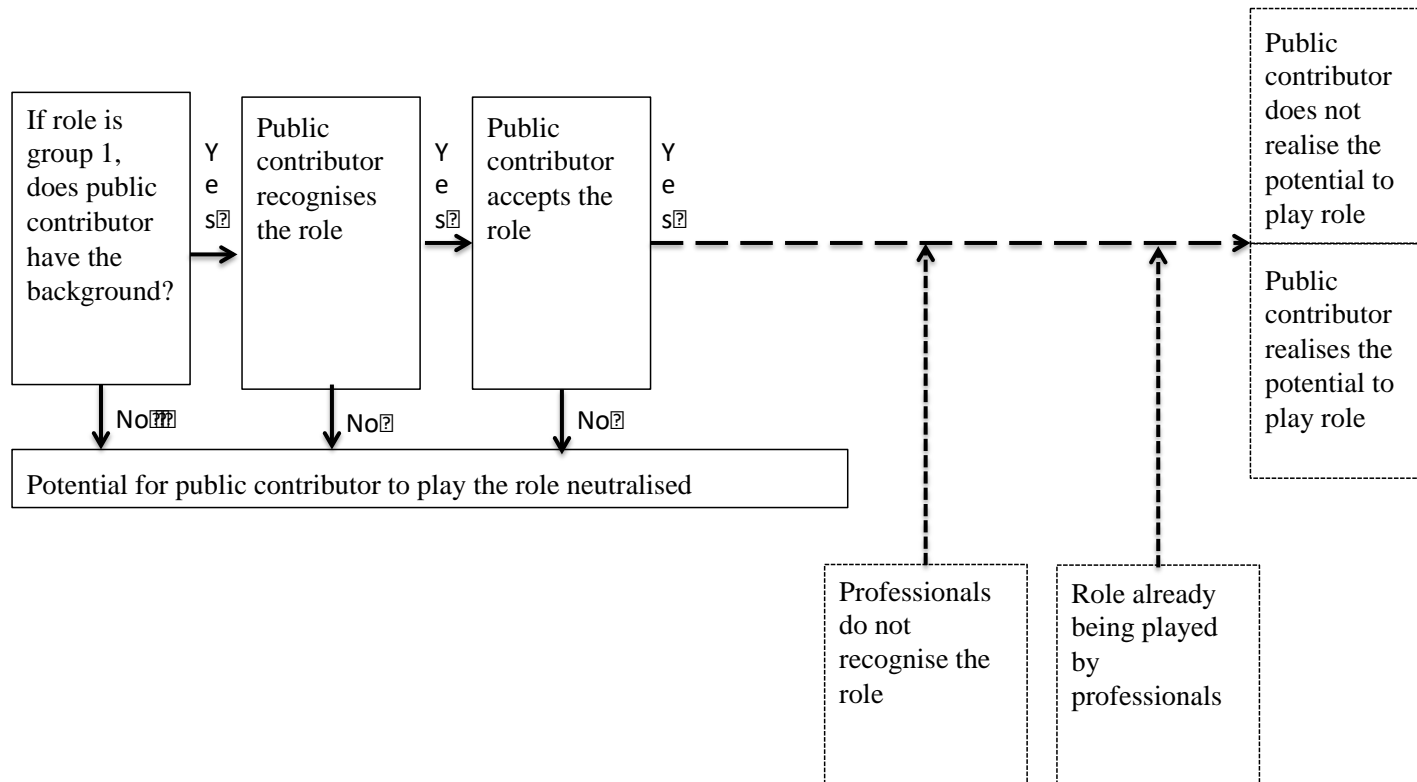


**Figure 5.1 A public contributor's potential to play group 1 roles**

Key: -

---> Potentiality for public contributor to play a role

-----> Forces acting on potentiality



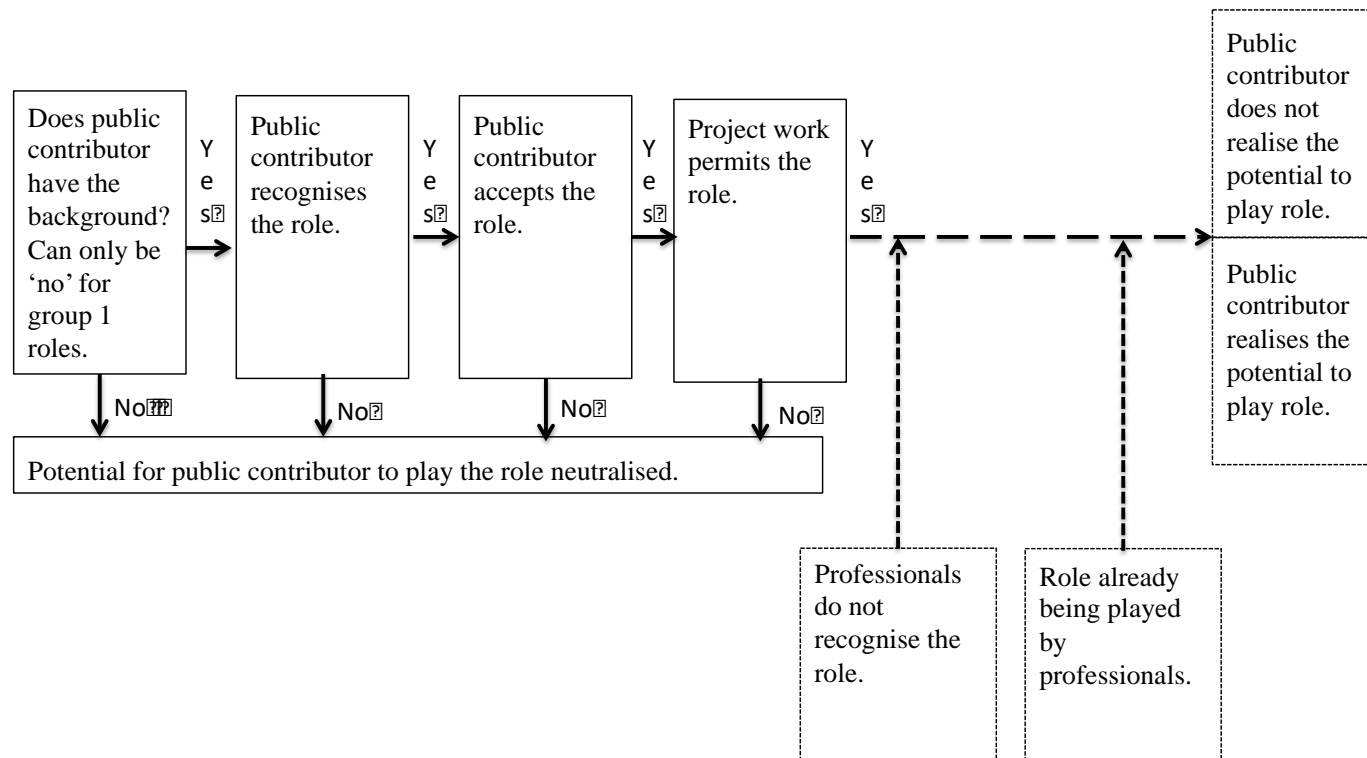
The sole group 2 role adds a further circumstance that may prevent the public contributor from playing some roles. The nature of the project work itself has to permit that role. This has been added to the diagram, shown in Figure 5.2.

**Figure 5.2 A public contributor's potential to play group 1 and 2 roles**

Key: -

— — —> Potentiality for public contributor to play a role

-----> Forces acting on potentiality



The group 3 roles highlighted the extent to which the public contributors' efforts enhanced the number of roles they could play. As shown in Figure 5.3 below, preparation such as reading the papers before meetings, and attending events and meetings outside the core requirement make it more likely that a role will be realised.

**Figure 5.3 A public contributor's potential to play group 1, 2 or 3 roles**

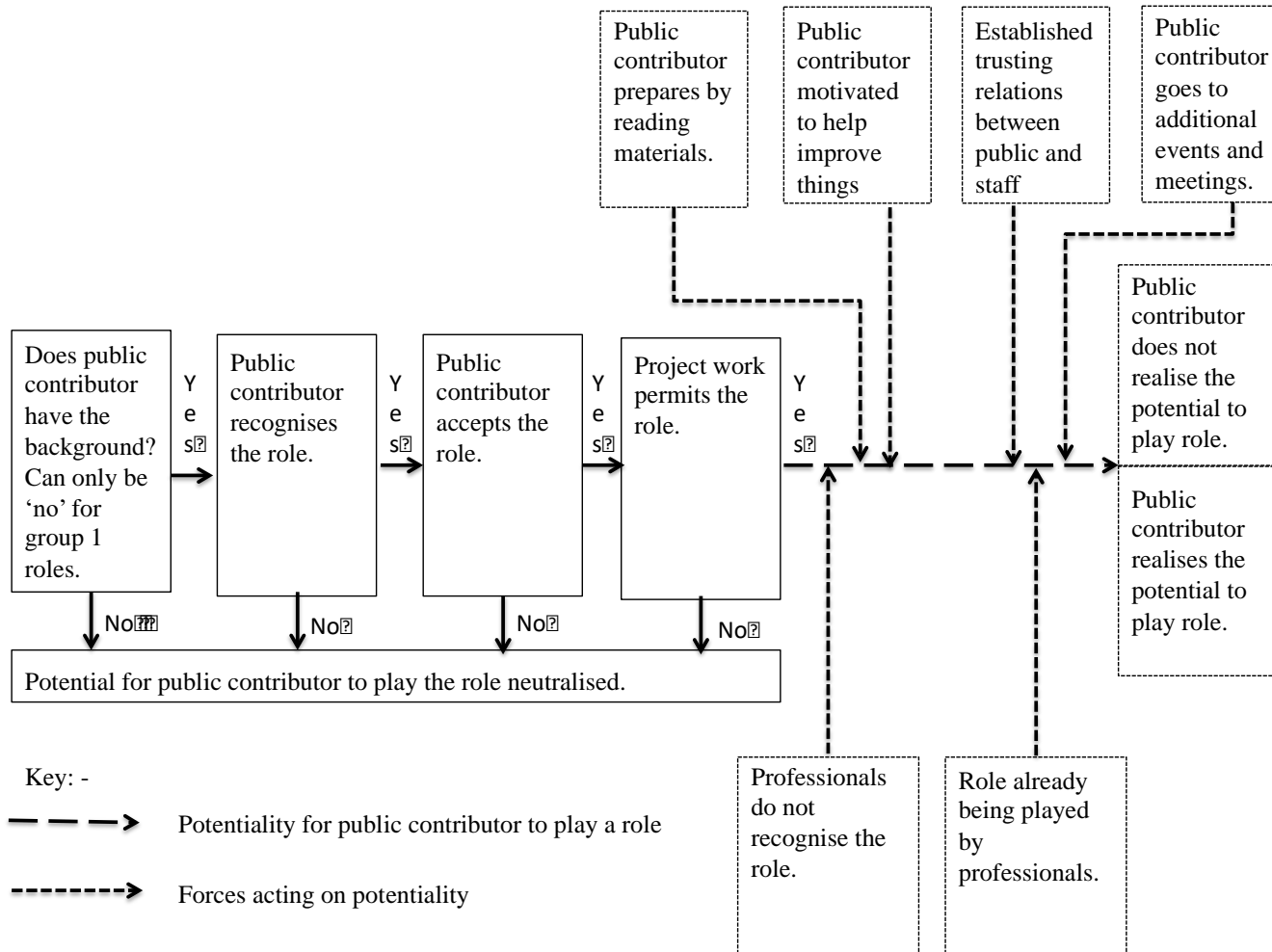


Figure 5.3 now shows the combined findings from all three groups of roles. For a group 1 role, the public contributor must have the qualifying background, or the potential to play that role is not realised. For a role from groups 1-3, the public contributor must recognise and accept a role in order to possess the potentiality to play it. However, the potentiality can be neutralised if the project itself is scoped so as to exclude the role. If the project permits, then the public contributor's potentiality to actually play the role is still subject to influences. If the professionals do not recognise the role or if the role is already being played by a professional then the potential to play the role may not materialise. On the other hand, if a public contributor prepares before meetings, is motivated to improve things, is working within established trusting relationships with professionals and attends additional events and meetings then the likelihood of playing the role is bolstered.

## **5.7 Functional variables - leadership**

The ION literature recognised the tension between efficiency and inclusiveness (Popp *et al.*, 2014). The more parties there are to a collaboration, the less efficiently the work will be done. As an NAO with 25 member organisations distributed across a large region, the AHSN faced the challenge of balancing efficiency and inclusiveness even without PPI. This thesis follows Huxham and Vangen (2005) who wrote that managing a collaboration is about managing tensions like this one. The management takes the form of soft or people skills because even where the collaboration is between organisations, the relationships are between people (Popp *et al.*, 2014). The PPI literature identified these soft skills as leadership, and associated them with senior team members (Evans *et al.*, 2013). However, in this thesis leadership includes a set of practices that mitigate the negative consequences of the particular involvement mechanism on the public contributors. Associating leadership with practices means it can be displayed by any team member rather than being the domain of the senior team members.

The PPI manager led the overall programme and matched public contributors to projects, overseeing the initial negotiations of format and schedules. However, the PPI manager attended only a handful of the project meetings, and could not lead the involvement inside the projects. Two strong approaches emerged. In both a specific

individual accepted formal responsibility for the involvement inside a project. One established a partnership between the PPI manager, the public contributor and a professional team member. The other approach placed responsibility for involving the public alongside including the member organisations. By contrast, leaving a project with no professional identified as responsible for PPI was associated with a narrow perception of the public contributor's role and an invitation that expired before the project ended.

The projects chose a range of different involvement mechanisms in their bid to balance inclusiveness and efficiency. Face-to-face meetings were associated with effective involvement by Rowe and Frewer (2005), because they minimised the loss of information flowing between parties. However, at the AHSN, lunchtime teleconferences helped working public contributors attend meetings. While the teleconferences were not a particularly successful mechanism in this instance, neither were any leadership practices deployed to mitigate the negative consequences. As well as action on the low audio quality, basic meeting management such as calendar notifications, explicit acceptance of meeting invitations, advance agendas, and sensitive timing of *ad hoc* calls would all have assisted. Leadership practices such as finishing each call by asking participants to identify themselves and contribute AOB would have ensured that no participant went undetected. Finally, a check-in with the public contributors part way through the project, might have elicited a dialogue about what could be improved. While they are face-to-face, large, formal, infrequent meetings are imperfect involvement mechanisms. The PPI literature identified informality as a way of building trust (Evans *et al.*, 2014), so formal meetings may not contribute towards building trust. Sporadic involvement is seen as less effective (Staley, 2009). In addition, large review meetings appear unlikely to yield opportunities for co-production, sometimes seen as an indicator of effectiveness (Crepaz-Keay, 2014). However, thoughtful leadership practices can mitigate the intimidating feel of large, infrequent meetings filled with high-status attendees. The chairperson can deploy helpful leadership practices by issuing specific invitations: to contribute to the agenda, comment on updates, or speak up during AOB. In addition, the chair can reinforce points made by the public and add action items. Formal meeting administration such as issuing an agenda beforehand and reliably ensuring that the

public contributors were included on the email distribution list play an important part. However, other professionals can also deploy leadership practices aimed at improving public involvement. Anyone at a meeting can introduce themselves in a way that de-emphasises their status. Anyone can be ready to explain difficult issues or volunteer or request explanations when they see the public struggling. Anyone can respond thoughtfully to the input the public do make. Finally, although sporadic involvement might not be ideal, it might be more manageable if everyone, professionals and public contributors alike, is included sporadically. Large, quarterly review meetings may also hold indirect opportunities for further involvement and for co-production as occurred in two out of the three AHSN projects. Thus, initial involvement in less than ideal circumstances can lead to future co-production.

*Ad hoc* meetings, the final involvement mechanism at the AHSN, are necessarily unplanned, responsive and may be urgent. The initial negotiation over scheduling does not extend to these meetings. However, especially in the absence of minutes or other formal outputs, scheduling them to go ahead without timing them sensitively risks excluding the public contributors. Once the public contributors have been excluded from one meeting, they may then be excluded from anything decided or arranged during that meeting, leading to a chain of exclusions. Scheduling meetings around public contributors at the beginning made them feel valued, continuing to schedule meetings around them might prolong that feeling of value.

The findings offered little evidence of leadership practices being shared between professionals and projects. Those professionals with ideas for improving the leadership of involvement during meetings had neither tabled those ideas nor discussed them with public contributors. Only one project provided evidence of mid-course dialogue between the professionals and a public contributor concerning how the involvement was working and how it could be improved. On the whole, the leadership practices displayed were those the professionals thought might assist the public contributors, rather than ones identified through dialogue. Perhaps Crocker *et al.* (2016) advise public contributors to request feedback from professionals because it is one way of initiating this dialogue.



The evidence from the AHSN contained multiple examples of leadership practices by chairs and other professionals. Many professionals saw adapting their behaviour to better involve the public as part of their role. Leadership practices give the public the opportunity to speak. In order to speak, the public contributors must be present (due to scheduling, and conceiving the role as lasting throughout the project), and to feel party to the conversation (by being up-to-date, by being invited to interject). While leadership practices give public contributors the opportunity to speak, legitimacy gives them something to say. Playing a range of roles helps the public to make a contribution when invited to speak. The invitation to speak can come in the form of a request to add agenda topics, to comment after updates, and/or to add an item to AOB. Access to a range of roles gives public contributors something to say across a wide range of topics. By contrast, if the public contributors play only a lived experience role, some opportunities to speak pass by.

## **5.8 Functional variables - power**

Power is explored here using the three circuits from Clegg's (1989) Circuits of Power model (reproduced in Figure 2.11). Most of the evidence shows power relations constrained to the first circuit, episodic power. Some evidence is considered in the light of the second circuit of power and explores the contestation of obligatory passage points. However, none of the data collected provided any evidence of innovations resulting in change to social relations. There was no evidence to suggest that PPI produced outcomes that transformed the rules fixing relations of meaning and membership, and thus did not access the third circuit of power.

Clegg's (1989) first circuit of power (see Figure 2.11) allows for power and resistance. Huxham and Vangen's (2005) work can be seen as a micro-level examination of how power and resistance play out in meetings in network collaborations. Here "there is not just one 'power baton' that may be passed around, but a multitude of batons that are not all made of the same material" (Huxham and Vangen, 2005, p. 185). The multiple points of power, power sharing, and resistance take place within a set of unchallenged standing conditions (made up partly of the

structural variables). In this circuit, the resistance and the power sharing do not result in any challenge to the overall status quo.

The AHSN initiation of PPI was one way of meeting government-set objectives on collaboration. During the recruitment process power shifted back and forth between the AHSN and the public contributors. For example, the public contributors held power while they decided to apply for the post, and while they decided to accept the subsequent appointment. The AHSN staff held power while they determined the criteria and selected the candidates. Thus, the public contributors were not powerless throughout the involvement process (as indicated by both Clegg, 1989 and Huxham and Vangen, 2005) but their moments of episodic power played out in the context of standing conditions that limited and constrained the scope of the involvement.

Even though public contributors attended the AHSN's board, the ultimate decision-making body, it is hard to escape the conclusion that the public did not share in the set-up of the standing conditions for PPI. The structural variables represent the organisation-determined standing conditions for PPI, and these were devised by the AHSN not in partnership with the public contributors. Some of the standing conditions were set for the AHSN by external organisations. For example, HMRC limited the occupational-based roles the public contributors could play and the wider NHS set the banding of the PPI manager role. Thus the public contributors possessed power during the involvement process, but their power and that of the AHSN staff was constrained by the standing conditions which in turn were only partly of the AHSN's making.

Reading the ION literature leads to contrasting expectations about power relations in an ION. On one hand, a network organisation sets up expectations of equalised or at least shared power relations (Popp *et al.*, 2014). On the other hand, mandated NAOs are close in form to single organisations and thus may exhibit familiar, hierarchical patterns (Popp *et al.*, 2014). The findings showed that, as well as the moments during the process where they held some power, some professionals used leadership practices to share power with the public, inviting them to speak, or add agenda items. Legitimacy, or the range of roles, allowed the public contributors to

take advantage of the power sharing. Thus within the first circuit of power, the findings offer evidence of the links between three of the functional variables, see Figure 5.4.

**Figure 5.4 Links between leadership practices, power and legitimacy**

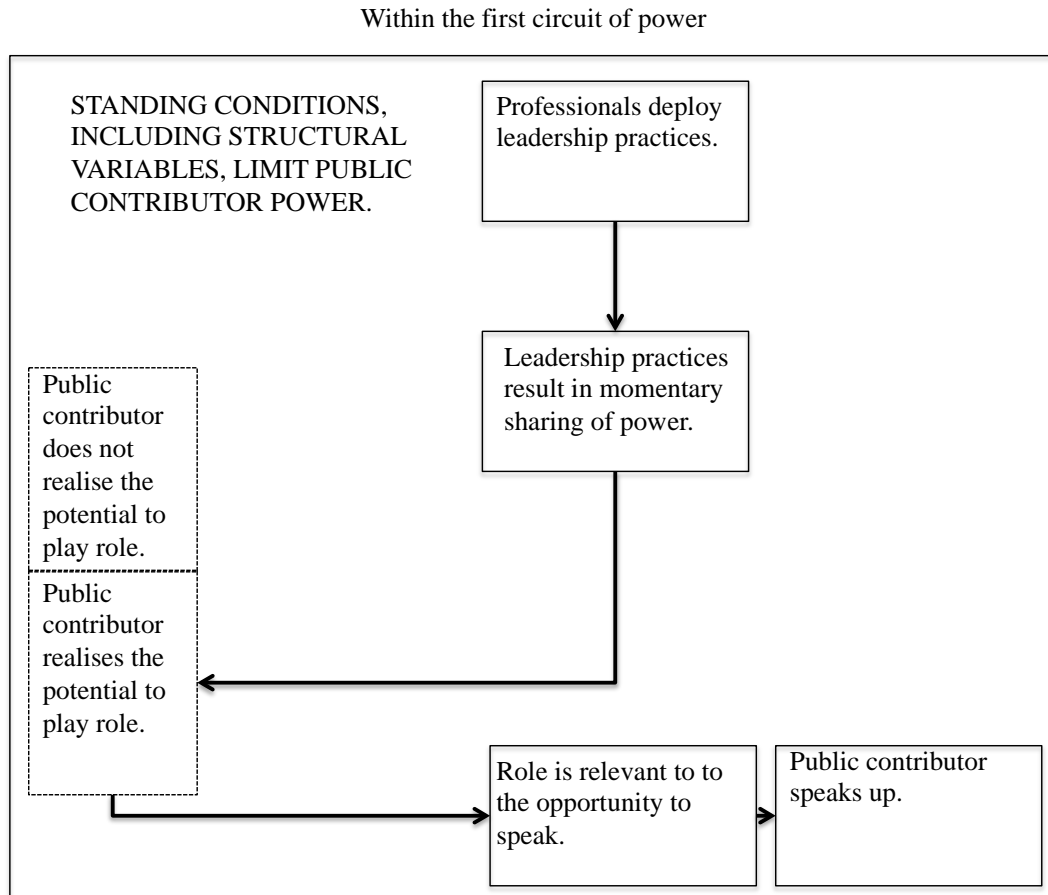


Figure 5.4 shows the link between leadership, power and legitimacy. Figure 5.4 also provides a link to Figure 5.3, which describes how public contributors realise the potential to play the roles. In deploying leadership practices, professionals share power with public contributors. Where public contributors possess the potential to play a relevant role, the momentary sharing of power gives them specific opportunities to play the role. Thus the momentary power sharing from leadership practices helps public contributors with the potential to play a role, to speak up based on that role. In this sense legitimacy is not, as Purdy (2012) described, a source of power. Rather, legitimacy is the basis for the voice the public contributors use, heard as a result of a momentary power sharing from professionals.

Several other factors affect the balance of power relations between professionals and public contributors. Shared or more equal power relationships were linked to trusting relationships in the ION literature (Brass *et al.*, 2004) as well as to network organisations. The standing conditions at the AHSN constrained the power of the professionals as well as the public contributors. For example, some professionals were excluded from the most senior meetings. Although the professionals used leadership practices to share power with the public contributors, the AHSN also provided evidence that the public contributors sometimes shared power in the other direction by conferring legitimacy on ideas raised by the professionals. However, the idea that some parties to a collaboration exercise power *in absentia* (Huxham and Vangen, 2005) demonstrates one of the ways in which the professionals' power exceeded that of the public contributors. Professionals could deploy power while absent using a number of mechanisms. First, the professionals sometimes sent deputies to meetings to speak for them. Second, professionals with positional authority sometimes had decisions from meetings referred to them. Finally professionals sometimes had discussions delayed until they could take part. The public contributors, on the other hand, needed to be present in order to exercise any power.

While most of the evidence fitted easily into the first circuit of power, one incident could be understood as an unsuccessful attempt to break into the second circuit (Clegg, 1989). One public contributor tried and failed to secure meetings without any professionals present. Using the model to understand the evidence, the public contributor can be seen as an agent attempting to contest an obligatory passage point, the right of the NAO to oversee all meetings. Without access to the email addresses of the other public contributors, budget, or facilities, the public contributor relied on the organisation for support. When the organisation withheld this support, the attempt to contest this obligatory passage point ceased, and the power relations continued to exist only in the first circuit of power.

The network form of the AHSN, its relative youth and its negotiation of its own role led to expectations of significant power sharing with the public contributors. However, the analysis shows that the moments of power held by the public contributors all occurred within the first circuit of power. Clegg called confinement

to the first circuit “the supreme achievement of power” (Clegg, 1989, p. 126), leading to the conclusion that the AHSN did not share significant power. While the standing conditions were not determined by the AHSN alone, it had significant authority, for example over the structural variables for the PPI programme. The AHSN determined its response to the public contributors’ attempt to meet. In this study, an NAO chose to allow power sharing with public contributors only in the most controlled way. While not dictated by the NAO form of the AHSN, this outcome is certainly consistent with it. The expectations of significant power sharing with public contributors may be more appropriately placed on more emergent, less controlled forms of network.

## **5.9 Functional variables - trust**

The ION and PPI literatures treated trust differently. The PPI literature associated trust with long-term relationships and regular involvement (Evans *et al.*, 2014). The ION literature, with its wider perspective on collaborations, suggested that trust is not necessarily built up with more exposure. Rather, trust needs to be built and then rebuilt in a continuous cycle (Bryson, Crosby and Stone, 2006; Huxham and Vangen, 2005). Kelman, Hong and Turbitt (2013) found evidence that where network managers self-reported prioritising trust, this had a positive effect on outcomes, where prioritising power sharing or leadership practices had none.

The evidence from the AHSN, though, seems to confound both sets of expectations. Few of the relationships between professionals and public contributors had the opportunity to be long term. The AHSN was a relatively new organisation. Despite hours of observation little of the data captured explicit trust building activity (such as sharing food, Evans *et al.*, 2014). In at least one of the projects, the trust building could not have predated the data collection. The evidence of trust therefore requires recourse to the wider literature on trust.

First, there was no evidence of distrust between the professionals and the public contributors in the study. However, distrust and trust are two separate variables (Lewicki, Tomlinson and Gillespie, 2006) so absence of distrust does not necessarily indicate the presence of trust. Second, the perception of the AHSN as a

part of the English NHS seems to account for a starting condition of trust on the part of the public contributors (see Section 5.2). Although some professionals in the study expressed anxiety that public contributor trust would be absent in big meetings, or eroded by petty bureaucracy, none of the public contributors alluded to these issues. The findings appear to show that the professionals and the AHSN needed not to build trust in a cycle so much as to ensure that the starting condition of trust was not eroded.

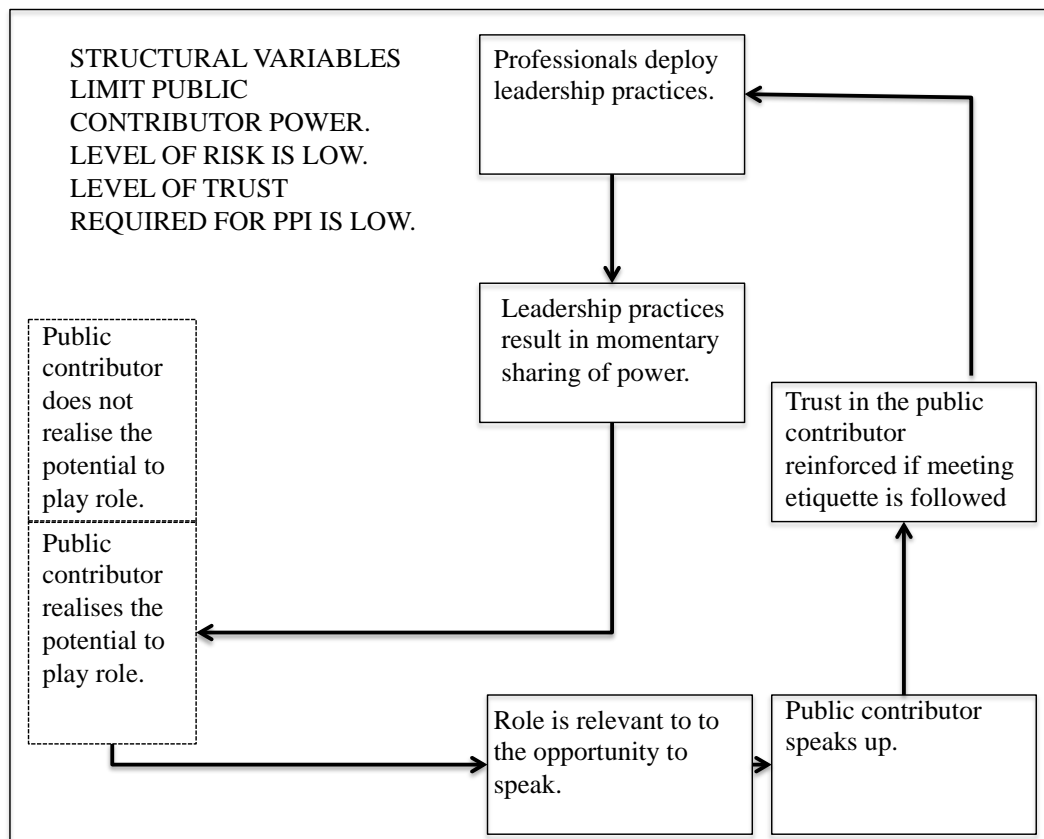
The professionals in this study mostly spoke about the way the public contributors reinforced the trust placed in them through adopting appropriate behaviour at strategic meetings. Thus the professionals also exhibited a starting condition of trust in the public contributors. For the professionals, this starting condition appeared to be related to the selection of appropriate public contributors for the strategic nature of the work. The selected public contributors then respected meeting agendas, the scheduled timing for items and the project aims. In other words, the public contributed according to the work processes and without disrupting them. This view is reinforced by the one incident that appeared to have undermined the professionals' trust in a public contributor. A public contributor (unwittingly) acted in a way not consistent with meeting etiquette by publicly criticising a junior staff member. The professionals at the AHSN had a set of expectations, then, about the nature and style of the public contribution. Where the contribution was seen as constructive, as conforming to good meeting etiquette, as recognising the difficult context, and as likely to praise as to criticise then it tended to reinforce the starting condition of trust. However, remarks that appeared to be personal and directed at a junior staff member could potentially undermine that starting condition, as could mistimed stories, insisting on debating issues the government had dictated, and taking meetings off at tangents.

While the analysis so far demonstrates a level of trust between the professionals and the public contributors, the findings still showed less evidence of trust than expected from the review of the collaboration literature. An explanation is offered by Mayer, Davis and Schoorman (1995) who equated the trust required in a collaboration to the risk the parties take. The structural variables here helped to establish standing conditions of power such as, for example, the nature of the invitation, and the

narrow public selected. These selections meant that the organisation and the professionals did not need high levels of trust in the individual public contributors. If the organisation had ceded more power, and risked more, then trust might have been a more important part of the findings here. The discussion of trust can be added into the diagram developed in Figure 5.4 to produce Figure 5.5 below.

**Figure 5.5 Links between leadership practices, power, legitimacy and trust**

Within the first circuit of power



**5.10 Functional variables – propositions**

Proposition 3.1 said, the functional variables can be used to describe how PPI in an inter-organisational health network operates. Figure 5.5 shows that the variables legitimacy, leadership, power and trust can be used to describe how PPI functioned. However, aims and objectives did not have the same explanatory power. Furthermore, aims and objectives did not fit into the explanation showing how the functional variables all link together. Thus proposition 3.1 has been amended to: the functional variables of legitimacy, leadership, power and trust can be used to describe how PPI at a health network operates.

Proposition 3.2 said, the functional variables affect the effectiveness of PPI in an inter-organisational health network. Figure 5.5 shows how the functional variables legitimacy, leadership, power and trust combined to affect the effectiveness of PPI. The professionals' leadership practices shared power with the public contributors in meetings, giving them the opportunity to speak. Where the public contributor could play a role relevant to the subject under discussion the public contributor used that opportunity to speak. As long as the public contributor spoke in a way consistent with the unwritten rules of behaviour governing the meeting, the starting condition of trust was reinforced. Thus proposition 3.2 has been amended to, the functional variables of legitimacy, leadership, power and trust affect the effectiveness of PPI at a health network.

The analysis of the functional variables provides further evidence that when NAOs select structural variables consistent with their hierarchical form, the standing conditions of power are such that the PPI programme is easily constrained to the first circuit of power. An organisation that cedes little power, takes little risk, and thus the PPI programme at an NAO may not require a high level of trust in order to operate.

### **5.11 Extent of the involvement**

SNA, a tool used with PPI for the first time in this study, explores the number and strength of links between public contributors and professionals. The PPI literature offered no comparisons with involvement in other settings. The ION literature did not predict the way the network maps showed the public contributor involvement in the context of the connections between professionals. Here the number and strength of connections between professionals provided a way to gauge the level of public contributor connectivity. Where the public contributor connections appeared similar to the connections between professionals, then the involvement was extensive. Where the public contributors had fewer, weaker connections than the professionals in the same project, then the involvement appeared to be less extensive.

However, even where the public contributors' connections displayed a similar pattern (in number and strength) to the connections between professionals, the



frequency differed. In all cases the public contributors' connections occurred less frequently than those between professionals. This finding shows that even extensively involved public contributors were outsiders to the health network when compared to the professionals. This finding is consistent with the roles listed in Table 5.1 which all rely to some extent on the outsider status of the public contributors.

The network maps yielded a further insight. The extensiveness of the involvement depended not only on the programme and the professionals, but also on the individual public contributors. For example, two public contributors with similar backgrounds, who play a range of roles, and who both have power shared with them through leadership practices can be involved to very different extents. The models developed in Figure 5.3 and Figure 5.5 capture differences between public contributors in terms of whether they realise the potential to play different roles, and whether the nature and style of their contributions reinforce the starting conditions of trust. The network maps reinforce the message of these models: involvement is a dialogic phenomenon and occurs between professionals and public contributors, and both have a part to play in determining its extent.

The network maps also highlighted the absence of strong relationships between the public contributors. The AHSN deployed public contributors in pairs, in line with best practice (Evans *et al.*, 2013). Even where public contributors start in a project at the same time and attend the same meetings in person, there is no guarantee that they will build up strong links with each other. If the purpose of deploying more than one public contributor is for them to support each other, then the evidence from the AHSN suggested that it can be ineffective unless the public contributors themselves see building strong mutual connections as beneficial.

Proposition 4.1 said, if public contributors are part of the inter-organisational health network then there will be evidence of multiple, strong links between them and the health network professionals and among public contributors. Based on the findings, proposition 4.1 has been restated to say, if the public contributors are part of the network then there will be a similar pattern of multiple, strong links between public contributors and professionals as there are between the professionals. Proposition

4.2 said, the number and strength of links between public contributors and professionals in the network is a measure of the extent of the PPI. Based on the findings, proposition 4.2 has been restated to say, the number and strength of links between public contributors and professionals compared with the number and strength of links between professionals in the network is a measure of the extent of the PPI. In this NAO, only two out of the five public contributors were extensively involved. The public contributors, as well as the professionals and the surrounding context play a part in this outcome. However, it would appear that a mandated NAO, which has constrained the power of the public contributors through the selection of key structural variables, which does not deploy network-based soft skills to the public, and which has not allowed the public contributors to meet together has not provided the most fertile ground for public contributor inclusion in the network.

## **5.12 Value**

Both the PPI and ION literatures suggested that evidencing value from collaborations is difficult. The two literatures shared some underlying assumptions with respect to impact (in PPI) and effectiveness (in IONs): the primacy of evidence-based knowledge and the dominance of institutional agendas. While involvement is accepted as a right (and a responsibility) for citizens, this thesis acknowledges that an evidence basis for proposed improvements is most likely to persuade professionals and institutions. Moreover, this evidence base is also held to be important for public contributors. After all, the public contributors in this study displayed high levels of uncertainty about the value of their contribution. A demonstration of that value, in the terms of the prevailing debate, could thus be emancipatory for the public. Hence, the next sections explicitly prioritise triangulated data in order to demonstrate value in ways that are not open to the accusation of being anecdotal. Furthermore, this thesis places the public, rather than the institution, centre-stage by assessing the contributions the members of the public actually made and demonstrating that the findings indicate value at the individual, client, community, organisation and network levels.

The PPI literature provided significant evidence of the effect of PPI at the individual level. The public contributors, in particular, benefited from new knowledge and skills as well as confidence, support, friendship and payment (Staley, 2009). None of the public contributors in this study mentioned confidence, support or friendship and the SNA reinforces the view that the public contributors at the AHSN did not derive support from each other while they worked on the same project. In addition these sources of value could be accused of being anecdotal. While payment is a source of value that could be corroborated, none of the participants mentioned payment in connection with the value of involvement. The only participant who commented on the payment at all made it clear that the payment was not a motivating factor and downplayed its value.

The benefit of an open search for value, centred on the public, is illustrated by the most significant evidence at an individual level. The coaching of a professional by a skilled public contributor was corroborated by two sets of interview data. The public contributor used occupational knowledge and skills to create this value, which may have been enhanced by the relative scarcity of marketing-related skills in the NHS. Coaching in this area may not have been readily available within the AHSN or its network. Here, then, the occupational knowledge role is tied specifically to value creation. While the PPI literature recognised the value of PPI to individuals, and specifically to professionals who are researchers, the categories were improved knowledge of the community, enjoyment from work, career prospects, and attitude towards the benefits of PPI (Staley, 2009). Coaching of a professional by a public contributor fits within the broad category, impact on professionals, but appears to offer a new sub-category, coaching by a public contributor.

In the health sector, the client level is primarily the patient, and by extension the carers and families of patients. None of the AHSN projects were specifically directed at these client groups. However, one project was aimed at the general public (rather than a specific community, or the AHSN's member organisations). For the purposes of this analysis, then, the value offered by the public contributors in this project has been included as a client level effect. The PPI literature suggested that the effect of the public was easiest to trace in relatively simple pieces of work such as leaflets and posters (Mockford *et al.*, 2012). Certainly at the AHSN, the

evidence demonstrated that the public contributors changed the wording in key ways. However, while these changes were aimed at the consumers of the materials, the ultimate impact of the changes on the consumers is unknown. This research could not use a control study to understand any impact on outcomes. The change to the wording is an intermediate outcome (Evans *et al.*, 2013). However, the findings do demonstrate the mechanism for the wording changes. The public contributors played two roles when they challenged the wording. As prototype publics they suggested changes to the refreshments and the registration. As fresh-eyed reviewers they spotted when the wording failed to reflect the project's stated aims and objectives. A control trial is not required to demonstrate the value here. Nor is evidence of a change in the final outcomes. Challenging the AHSN to change its execution in order to meet stated aims and objectives clearly delivered value both to the AHSN and its clients.

Involvement at the AHSN did not deliver any verifiable community level value during the data collection period. The one unsubstantiated claim to community value came from the sole public contributor who maintained close contact with a local, condition-specific group. Two explanations account for the lack of verifiable community level value. First, the AHSN recruited the public contributors based on their ability to take part in strategic meetings. This recruitment strategy did not result in a highly diverse group of public contributors, each spanning the boundaries between their community and the health organisation. Although it is worth noting that even where the recruitment strategy results in a more diverse group, there is no guarantee that the public contributors identify with that community, or see themselves as sharing their interests (Cornwall, 2008). While value at all the other levels relied merely on the public contributor being an outsider to the AHSN, value at the community level relied on them being an insider somewhere else. Insiders to particular communities may need to be specifically recruited as such. Second, the data collection took place within the NAO, rather than within the public contributor's networks. In this thesis, the case boundaries have been established as the organisation, and this has worked against the intent to challenge the institutional dominance of the evidencing of value.

The network level effects from PPI derived mainly from those instances where the public contributors influenced work aimed at member organisations. In the two instances of network value a public contributor used roles from the typology to prompt the organisation to stick more closely to its own stated aims and objectives. In one instance the effect was small, a change at a conference stall. In the second, though, the AHSN re-thought its entire plan for the education pathway at the heart of the project.

The findings also revealed two incidents of future potential network-level value. In one, the data collection could only confirm that the public contributor's idea had been passed on, and not whether it had been implemented. In the second, professionals took a minuted action to chase a local CCG to include their GPs in an initiative. In both of these incidents the public contributors' interjections led the AHSN to commit to negotiate with a member organisation. The ultimate outcomes were unknown because the data collection period finished before the actions were completed. These findings reinforce the difficulties of evidencing value in a network namely when should value be measured, and for how long afterwards (Harland, 2013)? The findings from the AHSN suggested an additional difficulty: where value should be evidenced if it might occur in the wider network.

The network level offers evidence of two other sources of value. First, the AHSN demonstrated a particular model of PPI, where public contributors are routinely involved in projects at a strategic level. The AHSN's PPI programme was characterised by its adherence to best practice guidelines (UWE, 2011) and the combination of a rigid expectation of involvement with a flexible approach to implementation. Second, the AHSN's PPI programme provided a space for the public contributors to play a wide range of roles, and to establish a basis for legitimacy that went beyond the lived experience. While additional roles have also been discovered in other settings (Crocker *et al.*, 2016), this much smaller study at the AHSN has discovered a wider variety of roles. The potential network-level value from these two instances comes because the AHSN involved the public and its members together in two out of the three projects. Thus professionals from the member organisations acquired direct experience of the AHSN's model of PPI. Even if this value is not fully understood or articulated by every meeting attendee,

there is the real possibility of future value accumulating if professionals from the wider network are able to use or share this practice in their work.

Proposition 5.1 said, extensive PPI affects value creation at one or more of individual, client, community, organisation or network levels. The value of PPI at the AHSN can be evidenced at all of these levels. Additionally, a key mechanism for delivering this value can be understood. When members of the public contributed, they used their range of roles and their outsider status to challenge the NAO to better implement its stated aims and objectives. Public contributors from all three projects created value in this way, even though some were extensively involved and some were not. Extensive involvement thus does not appear to be causally related to value creation in PPI programmes. Instead, the extensiveness of involvement appears to show whether citizens are really able to access their rights to involvement. Even when citizens are not extensively involved, they can still find ways to add value. For those who believe that involvement is a right regardless of value, SNA and the extensiveness of involvement could be used as a way to measure PPI. For those who believe that involvement is a right whose value should be understood and recognised, not least in the interests of public contributors themselves, the extensiveness of PPI and evidence of value at multiple levels can sit alongside each other.

The analysis of value prompts two further points. First, while centring the search for value around the public contributor has attempted to challenge the institutional dominance within PPI debates, it is worth noting that professionals are not required to demonstrate their value in the same way. The organisation and the network are required to demonstrate value, rather than individual professionals. This asymmetry arises because public contributors are individual citizens rather than members of a larger entity. Second, while this section shows evidence of value from PPI, the significance of that value is constrained by the scope of the project work. The most significant value here was the rethinking of the education pathway. This was value added to a backroom staff training and development initiative, so limited in the context of a strategic effect on the health network. The value of the involvement must therefore be weighed within the scope of the work the public contributors are

involved in. The scope of the work (a structural variable) has a profound effect on the significance of the value from the collaboration.

### 5.13 Refining the conceptual framework

The foregoing discussion means that the conceptual framework can now be refined, taking into account the changes to the propositions. This section steps through each component of the framework, before presenting the refined diagram.

The wider network(s) both constrains PPI by contributing to the standing conditions of power, but also acts as way to promote both the model and the practice of involvement. A mandated NAO form means the professionals use their soft network skills to establish the organisation’s legitimacy rather than to involve the public extensively. However, the constant negotiation over roles seems to facilitate a wide range of roles from the public contributors.

The structural variables of the PPI programme, which are shown in Tables 5.2 and 5.3, form the organisation-determined standing conditions of power. The choices made in this case were consistent with an NAO form and contained power in Clegg’s (1989) first circuit especially through control over the involvement invitation, the selection of public contributors and the scope of the projects. The confinement to the first circuit meant the NAO took little risk, and that collaborating required little trust.

**Table 5.2 Structural variables, overall PPI programme**

<b>Structural variable</b>	<b>Association with effective PPI</b>
Who initiates the involvement?	A strong role given to the other party, rather than the motivations of one party dominating the involvement.
Who is involved?	Involvement of a diverse population, selected for the purpose.
Diversity of mechanisms	Diverse groups are involved.
Critical mass of public	Public contributors have peer support.
Clear role definition	Public contributors and staff understand public’s contribution.
Budget	Funds are available to support involvement.
Involvement reactive or proactive	Permanently in place involvement (i.e. proactive).

<b>Structural variable</b>	<b>Association with effective PPI</b>
Public contributors supported to meet together regularly	Public contributors are supported in order to be effective.
Public contributors offered payment for their time	Public contributors are supported and valued.
Training for public contributors	To allow the public to develop expertise, if they wish to. Training denotes support for public contributors to be effective.
PPI led by a paid public contributor	To give public contributors access to decision making.
Public contributors on governing body	To give public contributors access to decision making.

**Table 5.3 Structural variables, individual projects**

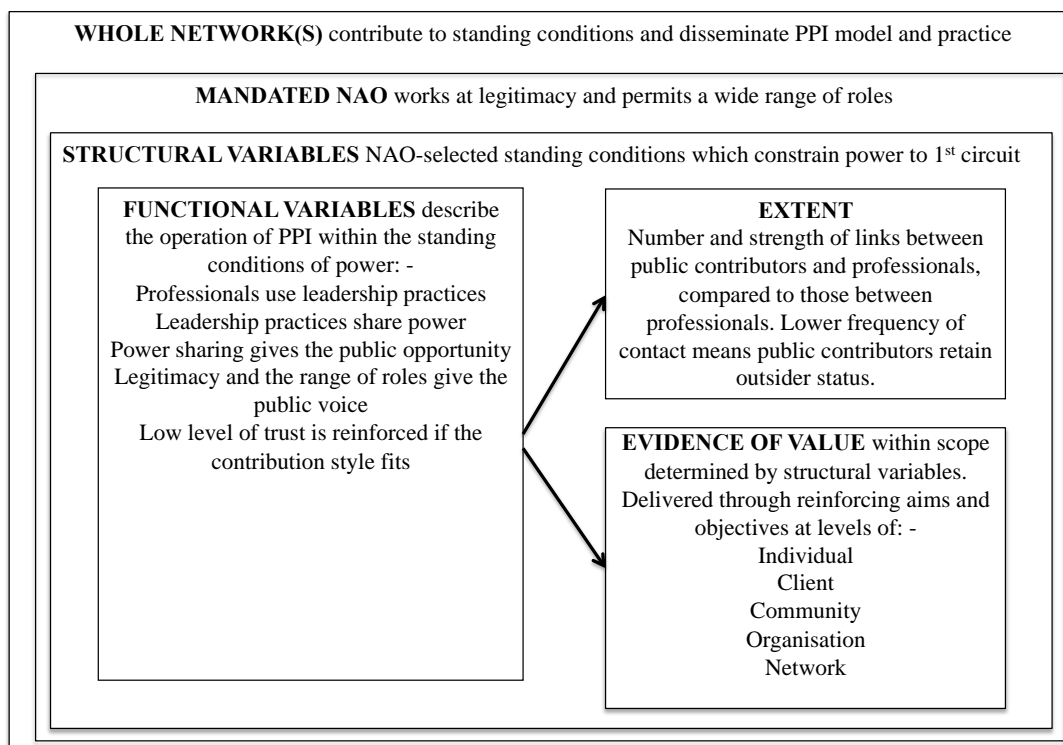
<b>Structural variable</b>	<b>Association with effective PPI</b>
Face-to face-involvement	To minimise the loss of any information flowing.
Facilitation	To minimise the loss of any information flowing and promote dialogue.
Depth of the interaction	Profound interactions.
Scope of the subject matter	Across a wide scope.
Consistent set of managers	Aids relationship building.
Involvement from the beginning	More scope to influence the agenda at the beginning.
Involvement all the way through	Regular, rather than sporadic involvement.
Information flow	Two-way leads to dialogue and changed understanding.
Public members contribute to official information	Demonstrates public contributor influence.
New initiatives are co-designed or co-produced	Demonstrates public contributor influence.
Speed	The timescales of the project should be generous enough to permit effective public contribution.
Professional experience of PPI	Previous experience of PPI amongst professionals seems beneficial. Where professionals have experience of engagement or participation, they may require assistance understanding the difference.
External parties	Where the project includes parties from organisations outside the NHS, the external parties may benefit from explanation and training to aid understanding of PPI.
More than one public	Where the project includes an involved public alongside an engaged and/or a participating public, the PPI may benefit from clear, shared definitions of each public and the roles they are playing.



<b>Structural variable</b>	<b>Association with effective PPI</b>
Involvement frequency	Frequent meetings (weekly or monthly rather than quarterly) seem to be associated with more effective involvement.
Project duration	Extended projects seem to be associated with more effective involvement than short projects.

The functional variables can now be presented to show the relationships between legitimacy, leadership, power and trust. Aims and objectives, however, have been moved to value as they were a key mechanism for public contributor value. The extent of the public involvement, shown through SNA, sits alongside value at multiple levels as a way of assessing public involvement. These changes are all displayed below in Figure 5.6.

**Figure 5.6 The refined conceptual framework**



The refined conceptual framework provides a way to think about PPI in complex organisational settings. It demonstrates that the influence of context is mainly through the standing conditions of power. Some of these are established outside the involving organisation (in this case by wider networks). Many of these are established when the involving organisation structures its PPI programme. The individual public contributors and professionals are not powerless in this conception, but they are constrained. Within the constraints, leadership practices matter because

they provide a way for professionals to share power (even if momentarily) with the public contributors, which gives the public the opportunity to play a role. The model suggests using two methods for assessing PPI, SNA and a multi-level search for the value centered on the public contributors. The twin assessments capture the right of citizens to be genuinely involved as well as the evidence that convinces all parties to involvement of its worth. The conceptual framework allows researchers in different settings to compare PPI programmes across those settings by understanding the nature of the context, the structure of the programme and the way the involvement functioned. A common approach across different settings means that evidence will cumulate so that general lessons about what different organisation forms mean for PPI can be drawn.

#### **5.14 Conclusion**

This chapter reviewed the findings in the context of debates in both the PPI and ION literatures. It set out each of the propositions and indicated where the findings supported, refuted or refined these. The amended propositions were incorporated into a revised conceptual framework. Despite the limitations of a single case study and the pragmatic approach to sample selection, the conceptual framework offers a common way for researchers to consider PPI in the light of a nest of organisational contexts, and to make comparisons across these contexts using a common approach.

## 6 Conclusion

### 6.1 Introduction

This chapter returns to addressing each of the five research questions. It sets out the limitations of this doctoral research in terms of both the single case, embedded unit design and the issues that emerged putting the design into operation. The contribution to theory is explored. Recommendations for practice for public contributors, those implementing PPI programmes and professionals more generally are suggested. Finally, the chapter turns to the recommendations for future research, focussing on how the conceptual framework developed here might be put to use in throwing light on the impact of organisational context on PPI.

### 6.2 What is the nature of the context that inter-organisational health networks provide for PPI?

This study held out the promise that an inter-organisational health network implementing best-practice PPI might provide an exemplar for involvement. Both the wider context of multiple networks, and the immediate NAO provided some support for this optimism. The key way in which an ION context benefits PPI comes from the opportunity to involve the public alongside professionals from the member organisations. This allows knowledge of the model of PPI and experience of the practice to disseminate through the network with the potential to influence network members in the development of their own programmes. A second key benefit for IONs in health is an association with the wide network of the NHS. This seems to account for a starting condition of trust from the public contributors to the professionals. Furthermore this study extended Ferlie *et al.*'s (2013) findings on the importance of clinical managerial hybrid professionals in IONs, showing that in mandated NAOs these hybrid professionals play roles that are fluid and subject to frequent change. This fluidity appears to extend to the roles the public contributors can play. The comparison of this study with Crocker *et al.* (2016) indicates that a mandated NAO form facilitates public contributors in playing many more roles than have been observed in other contexts. Finally, this study supports the findings of Ferlie *et al.* (2009) that professionals working in IONs do display soft skills such as negotiation and boundary spanning which have the potential to facilitate PPI.

However, IONs in health are not a straightforwardly beneficial context for PPI. The wide network context constrains PPI, contributing to the standing conditions of power and limiting PPI's potential to mount a serious challenge to the status quo. Radical involvement ideas are reigned in by the need to find consensus in support networks. Regulations, roles, pay grades and practices determined by the NHS and other parts of the wide network all limit experimentation by involving organisations. The NAO organisation form also fails to fully deliver on its promise as a beneficial context for PPI. In particular, the low level of internal legitimacy that Popp and Casebeer (2015) associated with mandated NAOs means that while professionals deploy network-based soft skills, they are not directed at the public contributors. Instead, skills such as negotiation and boundary spanning are directed at the member organisations in an attempt to keep the NAO relevant to members.

Provan and Kenis's (2008) typology of network organisational forms can be seen as a continuum. NAOs are at one end, closest to single organisation hierarchies (Popp *et al.*, 2014). Other network forms, especially emergent, shared participant-governed networks, at the other end of the continuum, may then deliver more completely on the promise of a beneficial context for PPI. In emergent, shared-participant governed networks, the professionals would possess the appropriate soft skills and internal legitimacy would be strong (Popp and Casebeer, 2015). This may leave the professionals more scope to direct negotiation and boundary spanning at the public contributors. However, external legitimacy would be weak. The risk, then, is that the professionals would deploy their soft skills to shore up this weaker external legitimacy, leaving the public contributors no better off.

### **6.3 What is the structure of PPI in inter-organisational health networks?**

The structure of a PPI programme can be described using the set of variables presented in Table 5.2 and Table 5.3. The structural variables are useful in providing a basis for comparing PPI programmes across different contexts. In particular, use of the structural variables facilitates a move away from contested terminology and definitions by describing who the organisation intends to involve and how, regardless of the labels given to the programmes and the mechanisms. In permitting comparisons of PPI programmes across different contexts, the structural variables

aid the identification of similarities and differences between contexts and thus the understanding of how different contexts affect an organisation's intent towards its PPI.

The structure of the PPI programme matters because the choices of who to involve and how to involve them establish elements of the standing conditions of power (from Clegg's 1989 model, see Figure 2.11). Some elements of the standing conditions are outside the authority of the involving organisation, for example tax rules and NHS practices. However, the structural variables represent those parts of the standing conditions that the involving organisations develop for themselves. Thus the structural variables are an important determinant of how much power is shared with the public contributors. Through determining how much power is shared, the structural variables also affect the level of trust required. Mayer, Davis and Schoorman (1995) showed that sharing power means taking risk and requires trust. Conversely, reserving power means taking little risk and requires low levels of trust.

In this study, the NAO selected a structure for its programme that was largely in line with best practice PPI. However, in key areas, the NAO chose to structure its PPI programme in ways that avoided sharing power with the public contributors. That is, the NAO issued a limited involvement invitation and tightly controlled who was invited in a way that severely restricted the diversity of public contributors. These choices appear to be consistent with a form that is close to single organisation hierarchies and thus relies on traditional forms of authority. An NAO can thus simultaneously appear to comply with best practice PPI and yet cede little power, take little risk and as a consequence require little trust as a collaboration partner. For effective PPI, it is thus important that all of the structural choices are ones that are associated with effective PPI, and not just the ones that allow the organisation to reserve power. For an NAO that initiates a limited invitation to a narrow public, constraining the PPI programme to the first circuit of episodic power (in Clegg's, 1989 model see Figure 2.11) is almost effortless.

#### **6.4 How does PPI in inter-organisational health networks function?**

The functioning of PPI is constrained because it occurs within a set of standing conditions. Some of these standing conditions are selected by the organisation in the form of structural variables. Within the standing conditions, the way that PPI operates in practice can be described with recourse to key variables, which capture the dynamics of the interactions between professionals and public contributors. In particular, the functional variables show how professionals and public contributors can maximise the opportunity presented by an involvement invitation. When professionals deploy leadership practices, they reduce power imbalances within meetings and can momentarily share power with public contributors. Public contributors can take advantage of the power share if they can establish their legitimacy based on a range of possible roles. Where the public can play a relevant role, they can interject, and where the interjections fit with the unwritten rules of the meeting, then this reinforces or maintains the professionals' trust. Within an NAO, not all professionals deploy leadership practices, and not all public contributors play a wide range of roles, or understand the unwritten rules of a meeting. However, the leadership practices of some professionals, and the range of roles played by some public contributors demonstrate how professionals and public contributors might maximise the opportunity presented by PPI, even where the structure of the PPI programme is not ideal.

The PPI literature suggested that the functioning of PPI would have the greatest effect on the success of the involvement (Evans *et al.*, 2014 and Oliver *et al.*, 2008). The ION literature, on the other hand, suggested that, in a network, functioning and structure act together to influence effectiveness (Provan and Milward, 1995). This study supports the view that structure and functioning act together. The structure of the PPI programme constrains the functioning of the involvement by establishing some elements of the standing conditions of power. In this study, the structure of the PPI programme constrained the involvement to the first circuit of power. Within the constraints of the PPI programme's structure, the functioning of the PPI can be more or less effective depending on the behaviour of the professionals (who can deploy leadership practices) and the public contributors (who can play multiple roles).

## **6.5 To what extent can public contributors be regarded as part of the inter-organisational network?**

Social network analysis can be used alongside value as a way to assess involvement. In particular, SNA shows the extent to which the public have been able to access their right to be involved, and this reflects on both the involving organisation and the skills and motivation of the public contributors. SNA goes beyond demonstrating that the organisation has a PPI programme and public contributors who attend meetings. SNA allows the assessment of the number and strength of the public contributors' links in comparison to those between the professionals.

The use of SNA as a way of assessing the public's access to their right to involvement offers a further possibility. The network maps offer an at-a-glance representation of how involved the public really are. Although the network maps must be read with care (Conway, 2014) they have a strong story-telling power. They are immediately accessible snapshots of the PPI programme unlike long reports and detailed assessments. The maps offer potential as a way to demonstrate some of the outcomes of PPI. In the Circuits of Power model (Clegg, 1989, see Figure 2.11) outcomes have the potential to be used to transform the rules fixing relations of meaning and membership. In other words, maps that showed that no public contributors ever built up strong multiple connections with professionals could be used to challenge the basis of an involvement invitation and potentially to break out of the first circuit of power.

Because SNA has not been used to assess PPI before, there are no other results with which to compare this study. However, in this study even the most connected public contributors were not connected as frequently as the professionals. The well-connected public contributors still appeared to be outsiders to the ION. In many instances, the value of public contribution from general citizens relied on this outsider status. Thus this study argues that the professionalisation of public contributors should not be feared. Even public contributors who appear integrated with the organisation in the form of multiple, strong links with professionals, connect to those professionals markedly less frequently than other professionals.

Public contributors thus appear to remain distinct from professionals in a network and can offer value in the form of challenge and fresh perspective.

## **6.6 How is PPI in inter-organisational health networks valued?**

This study aimed to complete an open search for value in a number of distinct ways. First, the study started the search for value with the contributions actually made by the public during the involvement programme. While direct observation of PPI is time-consuming and expensive it is important in this study as it places the actions of the public contributors, rather than the expectations of the professionals, at the heart of the search for value. Second, the study explicitly sought value at multiple levels: individual, client, organisation, community and network so as to be open to value wherever it should occur. Third, the study sought triangulated evidence in order to demonstrate value within the terms of a prevailing evidence-based debate in health, where uncorroborated evidence risks being viewed as anecdotal.

This study evidences value directly attributable to public contribution at all except the community level. Furthermore, the study identifies the public's outsider status as a key mechanism for delivering this value, in particular by challenging the professionals to deliver their own aims and objectives more closely. Even those public contributors who were not extensively involved, that is who did not have multiple, strong connections with the professionals could provide this value. Thus the extent of the involvement and the value deriving from it, sit alongside each other as complementary ways of assessing PPI. The SNA assesses the public's access to the right to be involved. The search for value at multiple levels provides evidence of the kind that is admitted by the involving organisations and their professional staff.

## **6.7 Limitations of the study**

It is important to recognise the limitations of this study in providing answers to the research questions. Single case study design is inherently limited. The findings cannot be generalised to a population. However, following Yin (2014), case studies can be generalised to theory. Ideally, the generalisations to theory would then be substantiated through a multiple case design, which either replicated the findings or



explained any differences. However, the scope of doctoral research confined this study to a single case. The wider research project focused on different aspects of the same AHSN, offering no possibilities for replication. The conceptual framework, while grounded in the extant literature, has not been substantiated through replication. Theory refined through replication to multiple cases has been described as “parsimonious” (Eisenhardt and Graebner, 2007, p. 30) compared with theory built on a single case study. Theory, constructed around an initial case, gets stripped down when reviewed in the light of findings from multiple cases. The methodology literature thus expects that replication will not support all of the relationships noted in the study of PPI at the AHSN.

The limited reach of a sole doctoral researcher, plus the chosen case study boundaries of PPI at one AHSN, permitted only limited examination of the wider network(s) as a context for PPI. A bigger study could have pursued the effects on PPI at the AHSN from interrelated networks. But all studies, even well funded ones, must impose limits somewhere, whereas the effects of action in an open, interconnected system flow across these artificial boundaries (Rittel and Weber, 1973) and potentially escape identification. In particular, the boundaries placed around this doctoral research affected the ability to collect data in the public contributors’ networks to verify community value, for example. Similarly, some examples of network value could not be corroborated without collecting data from AHSN member organisations.

Even with the embedded unit design, this doctoral research explored PPI in just three projects. The AHSN PPI manager suggested likely projects. This study avoided several projects managing the introduction of innovations, as these were the specific concern of other strands in the wider research project. These considerations, the restrictions over timing, and the limited total number of projects with PPI running concurrently at the AHSN meant that the three projects selected were the only candidates.

This research contains interviews with only five public contributors and 19 professionals. The small sample size also contained a gap. One public contributor did not agree to be interviewed. While the findings include observations from the

single project meeting this individual attended, they did not capture the views of a public contributor who ended their involvement part way through a project. The purposive sampling strategy aimed for maximum variation, but the recruitment of public contributors with white-collar backgrounds severely limited the variation possible in this part of the sample.

The research design included three separate sources of evidence (interviews, observation and document review) in order to promote triangulation. However, some aspects of the findings could not be corroborated. For example, just one participant talked about changes to public contribution over time. No other participant raised the subject at interview. The observations did not reveal this change over the data collection period. The document review similarly revealed no pertinent evidence. In one project, the start of PPI predated the start of data collection, so the change could have occurred during this period. This example demonstrates that this doctoral research explored PPI at the AHSN over a particular 16-month period.

The maximum variation sample selection for the three projects captured the different approaches to PPI in each. However, this also limited the comparisons that could be made between the projects. For example, only one project used teleconferences. In addition, this project alone made no adaptations to its leadership practices to promote involvement. Hence this doctoral research provides no comparison between face-to-face meetings and teleconferences where the PPI is explicitly led.

In some areas a single individual dominated the findings. For example, most of the evidence for three roles (occupational knowledge, patient advocate and boundary questioner) came from one public contributor. Indeed, only this public contributor played patient advocate. This public contributor stood out as a participant in this study in a number of ways. In attending more sub-group meetings, they had the opportunity to play a range of roles. In possessing not only a healthcare background, but one directly relevant to the project, they were the most specifically qualified public contributor. Not only are some of the roles dependent on one individual, the typology of roles (see Chapter 4, Table 4.3) shows only one role, prototype public,

in group 2. Whether other contexts will produce additional roles determined by the nature of the work remains to be seen.

The results of the SNA are presented in Chapter 4 as a network map for each project (Figure 4.2, Figure 4.3, and Figure 4.4). The three network maps exhibit “temporal grouping” (Conway, 2014, p. 105), where all the connections between project team members are represented as if they all existed for the entire period of the project, rather than showing the order in which they were built up. Some relationships may not have overlapped in time. The issue of temporal grouping means that network maps must be interpreted with care. A second issue relates to the recall of participants and their success in capturing all the connections that existed. Research has shown that, in general, respondents seem to be better at recalling those with whom they have strong links and are in routine contact (Marsden, 1990). This means that where professionals named public contributors, this was strong evidence that they had become part of the project’s network. Where professionals did not name public contributors, the professionals could have forgotten a weak connection. The potential issues with network maps do not appear to prevent an assessment of the strength and number of the links developed by public contributors.

## **6.8 The study’s contribution to theory**

This study’s contribution to theory comes from the conceptual framework. The framework synthesises two separate bodies of literature: IONs and PPI. First, this synthesis provides an approach to a key problem, the challenges of integrating context in the understanding of PPI. PPI was widely recognised in the literature as context-specific. Yet explorations of the effect of context were limited. The framework uses the ION literature to categorise the involving organisation as a particular type of ION, associated with specific characteristics and ways of working. Comparing these characteristics and ways of working with analysis of the enablers and barriers of PPI allowed the development of propositions designed to explore the nature of the involvement. The categorisation of the organisation then permitted the results to be generalised beyond the site of data collection by examining which findings were the case at the AHSN, and which must be the case at any NAO. While the framework as used here focused on PPI at an ION, the method used to build the

framework and synthesise the PPI literature with a part of the management literature is applicable to other organisation types. This type of knowledge integration could then promote knowledge accumulation (Rousseau, Manning and Denyer, 2008) about the strengths and weaknesses of different organisational forms as a context for PPI.

Within the framework, the structural variables highlight the organisation's commitment to sharing power with the public through the choices made. Further, the distinction between the structural and the functional variables provides a way to examine the difference between the organisation's intent and the way PPI operates in practice. The framework not only identifies the important functional variables from the literature synthesis, it also shows the relationships between them and, for example, how leadership practices and legitimacy give the public opportunity and voice. The synthesis of the ION and PPI literatures also led to the use of SNA as a way to examine and compare the extent of the public's involvement. While there is seemingly widespread recognition of the public's right to be involved, there is also widespread concern that involvement can be tokenistic. The use of SNA to assess the number and strength of the public's connections in comparison to those between professionals provides a method for demonstrating whether the involvement goes beyond the tokenistic. Finally, the framework uses the synthesis of the literatures to provide a structure for an open search for value at multiple levels. It highlights the public contributors' key mechanism for delivering value by using their outsider status to prompt organisations to more fully deliver their original aims and objectives.

## **6.9 Recommendations for practice**

This section provides recommendations for public contributors first, then for those implementing PPI programmes and finally for professionals. In IONs, this thesis demonstrates that public contributors can establish a broad base of legitimacy as general citizens who are outsiders to the involving organisation. Public contributors need not have a health condition, nor be inexperienced at involvement, untrained in the work or represent others. They need only be outsiders who want to help, are willing to draw on their background, do the preparation, and attend whenever

possible. Within the scope of the work available, public contributors can maximise their contribution by drawing on a wide range of different roles so that they have the basis for speaking up whenever the opportunity arises. This thesis offers public contributors detail on each of the range of roles, and shows how other public contributors have played them. Dissemination and discussion of the range of roles, together with examples of practice form the first recommendation for the public. Arming themselves with the range of roles may reduce the uncertainty some public contributors seem to feel when they become involved in activity outside their lived experience as patients. In turn this should allow public contributors to feel confident that they can add substantial value to decision-making throughout the English NHS, in particular by challenging professionals, projects and organisations to implement their own stated objectives.

For those organisations and individuals implementing PPI programmes, the key recommendations emerge from the way the structural variables of PPI form the standing conditions of power. Near compliance with best practice can result in little power sharing with the public contributors. In order to collaborate meaningfully, organisations must take a risk and cede some power. If organisations do not structure their programmes so that power is more shared then the value of the involvement will be constrained, and in an ION, the PPI model disseminated across the network will not be innovative. For existing PPI programmes, the structural variables could provide an audit checklist for joint teams of public contributors and professionals to assess against. For new PPI programmes, the structural variables and their link to effectiveness can guide set up. Inviting diverse public contributors to co-create the PPI programme using the structural variables as a guide would appear to provide a robust way forward. For involving organisations that are part of an ION, inviting members to a co-produced initiation would mean that this element of the overall model could be disseminated across the network. For involving organisations in an ION this approach would take advantage of the opportunity to promote adoption and spread of new ways of approaching PPI.

As well as their effect on the power relations of PPI, the structural variables can facilitate other elements of involvement that either an audit or a co-production team can keep in mind. Written role descriptions should be compiled with an awareness

of the range of roles public contributors can play, so as to encourage that range. For PPI programmes in IONs, the structure of the programme could explicitly encourage professionals to deploy their network-based soft skills for the benefit of the involvement. For example, a formal review point midway through the public contributors' terms would encourage negotiation over what is and is not working. As another example, the PPI programme could encompass the possibility of setting up mentoring relationships between professionals and public contributors (and the mentoring can flow both ways between the individuals). As a final example, the structure of the PPI programme could promote understanding that all involvement mechanisms have strengths and weaknesses. Part of the discussion about how, where and when to bring people together for co-working could include discussion of the specific barriers to effective involvement for that mechanism and how those might be mitigated.

For professionals working alongside public contributors, the functional variables show that even within the constraints of the programme's structure, individuals can make a difference by deploying leadership practices. This study shows that public contributors with white-collar backgrounds benefit from leadership practices aimed at reducing power inequalities and sharing power. By extension, public contributors with less experience in white-collar settings can be expected to benefit at least as much. Furthermore, many of the leadership practices are not the exclusive domain of the meeting chair and can be deployed by any professional.

## **6.10 Recommendations for future research**

The implications for future research from this thesis focus on the conceptual framework, in particular in the route it gives to understanding a PPI programme in a complex ION context. The key need is to use the framework to explore the furthest end of the ION governance continuum in order to draw comparisons with NAOs. This would mean examining PPI at emergent, shared-participant IONs to see whether moving along the continuums from NAOs is likely to facilitate involvement because there is less and less reliance on traditional, hierarchical forms of authority.. However, the promise of a beneficial context for PPI in emergent, shared-participant governed networks still remains to be investigated, particularly where the members

and the public are involved alongside each other, where the PPI model is a significant step forward from that deployed by all the members and where the network's internal legitimacy permits the professionals' soft skills to be directed at the public. The risk is that the professionals in emergent, shared-participant networks direct their soft skills as building their external legitimacy.

The second line of questioning emerging from the conceptual framework is the extent to which the choice of power-preserving PPI structures is not just consistent with an NAO form but causally related to it. For example, future research could examine whether there are circumstances in which NAOs do cede significant power in their PPI programmes. Another approach might be to use NAOs that are just initiating their PPI programme as study subjects in an attempt to understand how and where key structural variables are being selected.

The description of how PPI functions in abstract terms demonstrates power as the most important functional variable. Furthermore, the abstraction in the conceptual framework allows the application of models from theory to both explain how PPI functions and to suggest avenues for future research. Applying the Circuits of Power model (Clegg, 1989, see Figure 2.11) suggests that one way to break out of the first circuit is to challenge the obligatory passage points. Further research is needed to establish whether, for example, public contributors who organise independently of the involving organisation can mount an effective challenge here. For example, if public contributors can gather and distribute their own contact details, and can call upon independent resources to meet together unsupervised, then the organisation may not be able to restrict their activity so easily.

The other functional variables are important in terms of how they affect the power relations. Examining trust, for example, appears to provide a way to illuminate power in a way that is accessible to researchers. Further research is needed to establish whether the absence of trust-building activity, and cycles of trust, always indicate that a PPI programme has not ceded any significant power to public contributors. Further, asking questions about trust might allow researchers to short-circuit long hours spent observing the functioning of PPI in organisations,

potentially freeing up research time to collect data outside the involving organisation and out into the network of members and public contributors.

Leadership practices are important to the way PPI functions mainly as a way to address power imbalances within meetings by sharing power (even if momentarily) with public contributors. Leadership can be shown by any professional, and can mitigate the effects of less than perfect involvement mechanisms. This study suggests abandoning the search for perfect mechanisms (such as suggested in Rowe and Frewer, 2005), but focusing instead on the types of leadership practice that most effectively lead to power sharing with the public contributors. In addition, further investigation is required to understand whether leadership practices can mitigate the distancing effects of teleconferences so that they are as effective a form of involvement as face-to-face meetings.

Legitimacy operated in specific ways in a mandated NAO. The negotiation over roles seemed to create a specific context for the public to play a wider range of roles than has been observed in other contexts. Further research could establish whether this negotiation over roles, and the subsequent wide range of roles played by the public contributors is a common feature of NAOs. Further research could specifically target the exploration of the known roles and the further population of the typology presented in Table 5.1. This research opens up a new line of questioning for researchers, to see if IONs with higher levels of internal legitimacy still hold open a wide range of roles for public contributors using a different mechanism, or whether this aspect of public contribution suffers in different forms of network governance.

The initial use of SNA in this thesis offers multiple lines of enquiry for future research. First, SNA in other cases will offer comparison and the extraction of common themes and mechanisms. Second, SNA could be used to capture dynamic change in PPI programmes. Using longitudinal study, with SNA captured over time, researchers could establish what can transform the links between public contributors and professionals. Third, the network maps produced by SNA could be used for network engineering (Barron, Scarlett-Ferguson and Aspen, 2015) that is, to specifically encourage the development of links between the public and



professionals. Finally, the network maps could be used as part of the professionals' reflective practice (Kothari *et al.*, 2014) in an action research setting.

Finally, this study prompts ways to further release the assessment of value from dominance by the institutional agenda. First, evidence-based value could be important to public contributors. Second, widening the conception of the case boundaries may provide fruitful lines of enquiry. The open search for value should travel out to both network members and to related communities of which the public contributors feel a part.

### **6.11 Concluding Remarks**

As PPI and IONs continue to be parallel policy responses to wicked problems in health, an accumulation of knowledge in how the two endeavours interact continues to be important. This study shows that there is an opportunity to further exploit IONs as a beneficial context for PPI. Because IONs are built around bringing different parties together to collaborate, an NAO offers public contributors the possibility of playing a wider range of roles than a single organisation hierarchy. However, the need of a mandated NAO to labour at internal legitimacy means that the professionals direct their soft skills at being relevant to the members, rather than at involving the public. Thus relieving the low internal legitimacy, including the public along with the members, or making relevance to the public as important as relevance to the members all offer possible routes to more fully realising the opportunity.

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## Appendix 1 - abbreviations list

AHSN	Academic Health Science Network
AOB	Any Other Business
CCG	Clinical Commissioning Group
CEO	Chief Executive Officer
GP	General Practitioner
GRIPP2	Guidance for Reporting Involvement of Patients and the Public 2
HMRC	Her Majesty's Revenue and Customs
ION	Inter-Organisational Network
NAO	Network Administrative Organisation
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
PPG	Patient Participation Group
PPI	Patient and Public Involvement
PR	Public Relations
RCT	Randomised Control Trial
SNA	Social Network Analysis

## Appendix 2 - glossary

Aims	the overall intent of an endeavour
Contribution	any interjection or action by a public contributor
Engagement	when materials are shared with members of the public and when the opinions or views of the public are sought
Functional variables	variables showing how PPI actually operates day-to-day
General public	individuals who may have engagement initiatives aimed at them
Involvement	when public contributors work alongside professionals on healthcare projects
Objectives	the specific tactics for achieving an overall intent
Participant	a member of the public who is a subject in a research project
Participation	when members of the public are subjects in a research project. The research project is done 'to' or 'about' the individual (INVOLVE, 2015)
Professional	anyone assigned to a project as a result of their paid employment
Public Contributor	a member of the public who is involved
Structural variables	variables describing the organisational approach and intent, that is, the framework of rules, guidelines and practices governing PPI
Value	the changes attributable to a public contributor or an ION, in terms of the real and unintended effects. Value can encompass effects, outputs, outcomes, and impact

## Appendix 3 – public involvement in the doctorate

### Public adviser role description

- To review participant documents such as the patient information sheets.
- To review and proof read thesis chapters.
- To raise and correct any issues surrounding public contributors and to ensure that their perspective is captured, their issues are raised and that they have a voice in this study.
- To connect the researcher in to the AHSN to aid with access.
- To challenge and debate any aspect of the study.
- To meet the researcher regularly for the consumption of tea and cake and so that some of the above can be conducted face-to-face.
- To exchange with the researcher reading materials, ideas, references, in order to promote the general education of both.

### Public involvement report – GRIPP2

Staniszewska *et al.*, (2017) have established a set of reporting guidelines for PPI in research called GRIPP2. The short form version of the guidelines has been used below to report on the public involvement in this doctoral research.

Section and topic	Item
1. Aim of the study	To evidence the value of PPI at the AHSN by investigating the nature of the ION context, the structure of PPI, the way PPI functioned, the extent to which public contributors were part of the network and how PPI has been valued.
2. Methods	The public adviser was recruited and the role description (above) agreed six months into the doctorate. The researcher met the public adviser every six to eight weeks and discussed the research questions, the literature, the conceptual framework, and the progress of the data collection, data analysis and writing. In addition, the public adviser reviewed the patient information and consent forms, and each draft of the written thesis, providing both proof reading and comments on the content and style.
3. Results	The public adviser contributed in the following ways: - -suggestions for additional reading -changes to the patient information and consent forms -providing a sounding board for potential ideas and approaches -challenging faulty logic and ill-defined concepts -sharing the experience of being a public contributor -considering the findings in the light of his own experience -commenting on each draft of the written thesis

Section and topic	Item
4. Discussion	<p>The success of the public involvement in this doctoral research may have been related to the public adviser's experience in involvement and the adoption of best practice (such as regular involvement throughout the project and a written role description). The researcher and the public adviser had met and both participated in a PPI journal club, which had given them an opportunity to assess each other in advance of working together. As well as the personal chemistry, both the public adviser and the researcher had an interest in learning from each other. The public adviser was interested in the process of research and used involvement in the doctorate as a way to familiarise himself with various methodologies. The researcher learned from the public adviser's wide reading in philosophy. Finally, the involvement took place in a helpful context. PPI provided the subject of the research, the institution had a long history in PPI, and two of the doctoral supervisors had personal experience involving public contributors in research.</p> <p>The limitations arose partly due to the restrictions surrounding the doctoral process. The opportunities for co-creation were restricted to writing outside the doctorate (such as blog posts). In addition, a sponsored doctorate did not allow sufficient funding for payment for the public adviser. Although the researcher bought the café americanos and the cake at each meeting, these were small compensation for involvement in a three-year long process and in-depth review of thousands of words. However, the public adviser involved in this research commented on this appendix saying that where independence (in this case from the NHS and from academia) is prized, payment in kind might be better than a stipend.</p>
5. Reflections	<p>One issue here was the informality of the involvement mechanism. If this was repeated, then the public adviser might be invited to the regular, formal supervision meetings. This might have both allowed the public adviser greater insight into the doctoral process and provided a mechanism for involvement that was part of the standard doctoral process.</p>



## Appendix 4 – literature search

The table below sets out the key literature search terms and databases used to establish the lack of overlap between the PPI and ION literatures, and the subsequent examination of the concepts and ideas used when members of the public joined with professionals to work on difficult problems.

SEARCH TERMS SET 1	SEARCH TERMS SET 2	SEARCH TERMS SET 3
Patient*	‘wicked problem*’	Network*
Public*	‘messy problem*’	Not computer
User*		
Citizen*		
Lay		
DATABASE and SEARCH DATE	CRITERIA	RESULTS for ‘SET 1 and SET2’
Business Source Premier 8 <sup>th</sup> May 2016	Key word search of abstracts. English language only. All dates.	Set 1 – 1,003,171 results Set 2 – 193 results 1 + 2 – 54 results
	Manual title review for the public working on complex problems with professionals.	Review of 54 titles: - 9 selected for further review
	Manual abstract review for the public working on complex problems with professionals.	Review of 9 abstracts: - 1 already included in literature review 4 articles subsequently included in literature review
DATABASE and SEARCH DATE	CRITERIA	RESULTS for ‘SET1 and SET2’
CINAHL, MEDLINE, and PSYCHINFO 12 <sup>th</sup> May 2016	Key word searches of abstracts only.	Set 1 – 1,310,319 Set 2 – 98 1 + 2 – no results
DATABASE and SEARCH DATE	CRITERIA	RESULTS for ‘Set 1 and SET2’
ASSIA 12 <sup>th</sup> May 2016	Key word searches of abstracts.	Set 1 – 138,496 results Set 2 – 23 results 1 + 2 – 6 results
	Manual abstract review for the public working on complex problems with professionals.	Review of 6 articles: - 0 articles subsequently included in literature review.
DATABASE and SEARCH DATE	CRITERIA	RESULTS for ‘SET1 and SET2’
EMBASE 16 <sup>th</sup> May 2016	Key word search of abstracts.	Set 1 – 7,458,960 results Set 2 – 621 results 1 + 2 – 193 results

	Manual title and abstract review for the public working.	Review of 193 titles: - 10 selected for further review
	Manual abstract review for the public working on complex problems with professionals.	Review of 10 articles: - 1 already included in literature review 1 duplicate 7 discarded for not meeting the criteria 1 subsequently included in literature review

## Appendix 5 – case protocol

### Overview

The intent of this research is to evidence the value of PPI at the AHSN, collecting interview, observation and documentary data from three different AHSN projects involving public contributors. Data will be collected from both the public contributors and the professionals.

Statements about the research can be provided from the participant information and consent forms, see Appendix 6.

### Research questions, propositions and data sources

Overarching question: -

*What was the nature of PPI at the AHSN, and how has it been valued?*

Sub-questions and propositions: -

1. *What was the nature of the context that the AHSN provided for PPI?*

Proposition 1.1: If the PPI programme benefits from the NAO form of the AHSN then there will be evidence of staff deploying some or all of: negotiation, boundary spanning, teaching, coaching and mentoring skills.

Data sources: interviews and observations

2. *What was the structure of PPI at the AHSN?*

Proposition 2.1: The Structural variables can be used to describe the form of PPI at the AHSN.

Proposition 2.2: The structural variables do not affect the effectiveness of PPI at the AHSN.

Data sources: documents, interviews, observations.

3. *How did PPI at the AHSN function?*

Proposition 3.1: The functional variables can be used to describe how PPI at the AHSN works.

Proposition 3.2: The functional variables affect the effectiveness of PPI at the AHSN.

Data sources: primarily observation data, but also interviews and observations.

4. *To what extent could public contributors be regarded as part of the network?*

Proposition 4.1: If public contributors are part of the network then there will be evidence of multiple, strong links between them and AHSN staff and among public members.

Proposition 4.2: The number and strength of links between public contributors and professionals in the network is a measure of the extent of the PPI.

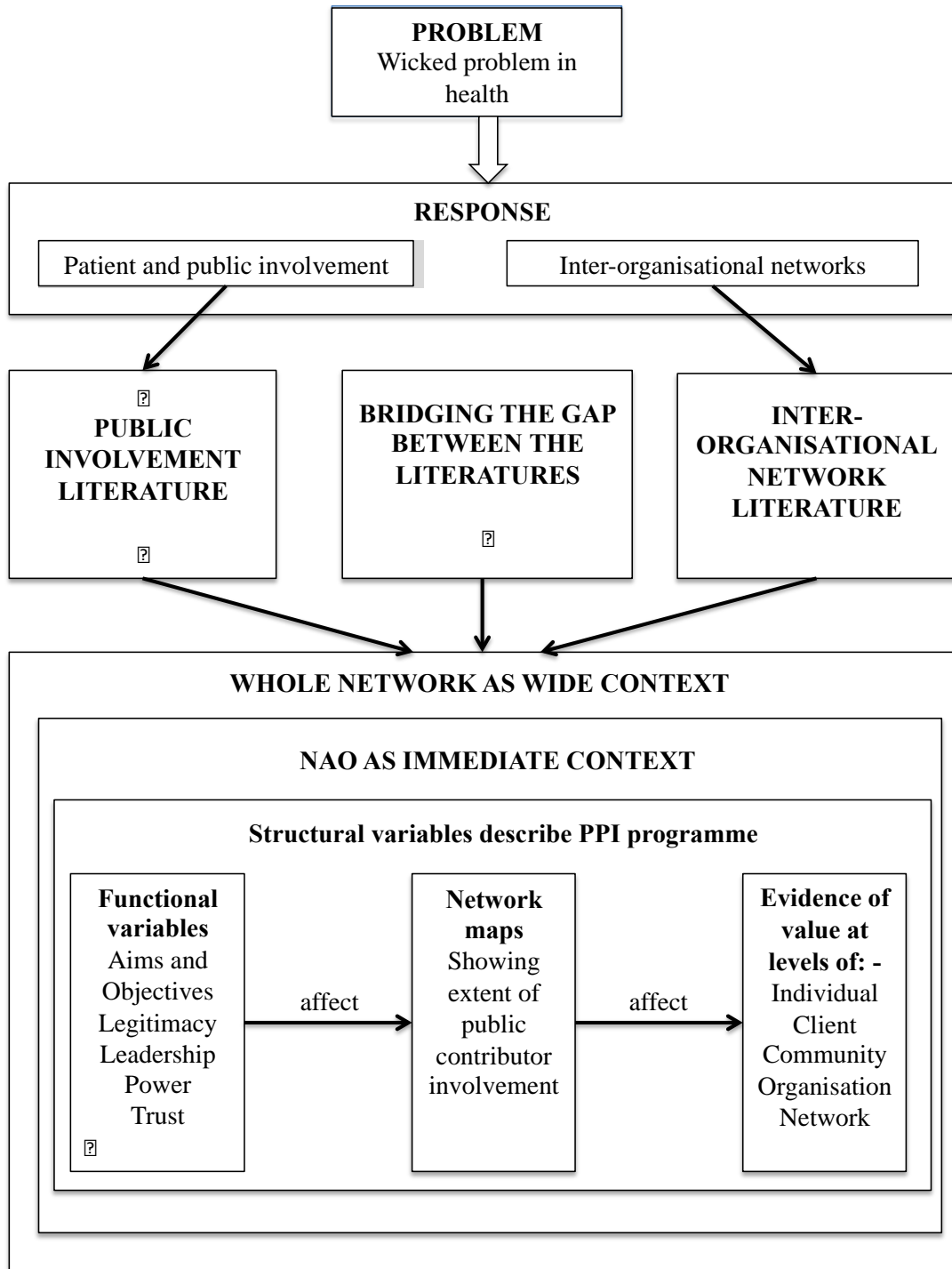
Data sources: interviews – SNA from the name generating questions.

5. How was PPI at the AHSN valued?

Proposition 5.1: Extensive PPI affects value creation at one or more of individual, client, community, organisation or network levels.

Data sources: document review, interviews, observations to track suggestions, and interjections by public contributors and the effects they have had.

**Conceptual framework**



## **Data collection procedures - observations**

### 1. At the very start of the meeting

- Ask the chair for the chance to introduce the research and obtain consent right at the start of the meeting.
- Introduce the research verbally using the participant information and consent forms.
- Pass out two copies of the information and consent forms to anyone who has not already signed them. Obtain both copies back, sign and date them, return one copy to the participant and retain the other copy for filing.

### 2. During the meeting

- Once consent has been obtained, start audio recording of the meeting.

### 3. After the interview

- Save the recording using the file naming convention 'YYYYMMDD\_project code\_meeting\_type\_observation'.
- Note any issues/changes/observations etc. in an analytic memo in the research diary or (if possible) direct onto the project database.
- Save file onto project database as soon as practicable.
- Send audio file for transcription as soon as practicable.
- When the transcription file is returned, save to project database using the same naming format as above and adding (2) to the filename.
- When the transcription file is saved to the project database, go through the transcript anonymising the transcript (i.e. use the project and participant codes in place of names, and obscure the region/cities/place names and the organisation name).

## **Data collection procedures - interviews**

### 1. Scheduling the interview

- Contact made either by email or after a meeting, which has been observed.
- All interview candidates have already read the participant information sheets and signed consent forms incorporating the interview (check).

### 2. Before starting the recording

- Reminder of the subject and purpose of the research (from the participant information sheet).
- Reminder that the consent form has already been signed (prior to observations).
- Reminder that there is the right to withdraw at any time.
- Reminder that a draft of the findings chapter will be sent to check that their anonymity is sufficiently protected and that their data has been presented accurately.

### 3. Interview topic guide

#### -Introduction

Role, length of service, professional background (for staff), experience of PPI in other circumstances.

Explore any background in PPI. Invite comparison with AHSN experience.

-SNA questions

Question 1 for public members only: Who is the lead in this project for your involvement? Explore the nature of this lead.

Question 1 for other project members: Who is your line manager?

Question 2 for all participants: Over the course of the project, with whom did you most often have meaningful discussions about the project? The discussions may have been over email, but not to an email list.

Questions 3: How often did you have meaningful discussions about the project with each name?

Questions 4: With each name, what was the nature of the meaningful discussions you had with them?

Question 5: Which of these individuals named have had meaningful discussions with each other about the project?

Question 6: How often did each of these names have meaningful discussions with each other?

-Questions about involvement in the project: -

How were public contributors recruited to the project?

How were public contributors involved in the project?

How did you understand the role of public contributors?

Did the role of public contributors change over time?

What factors facilitated the involvement of public contributors?

What factors impeded the involvement of public contributors?

Did any project team member take a lead in involvement? What was the nature of that lead?

Is there any evidence of the success indicators for PPI: Did the public contributors meet together? Get offered any training? Did they get paid?

Contribute to official information? Co-design the initiative? Did they sit on the governing body?

How were decisions made in the project? What was the role of public contributors? Could public contributors influence decision-making?

Anything the participant would like to say about PPI that has not been covered?

4. After recording

-Save file using date (YYYYMMDD)\_project code\_participant identification code\_interview convention.

-Back up the audio file as soon as possible after the interview.

-Note any issues/changes/observations etc. in an analytic memo in the research diary or (if possible) direct onto the project database.

-Save file onto project database as soon as practicable.

-Send audio file for transcription as soon as practicable.

-When the transcription file is returned, save to project database using the same naming format as above and adding (2) to the filename.

-When the transcription file saved to the project database, go through the transcript anonymising the transcript (i.e. use the project and participant codes in place of names, and obscure the region/cities/place names and the organisation name).

## Appendix 6 – participant information and consent forms

### Introduction

You are being invited to take part in a piece of research with the title “**Evidencing the value of Patient and Public Involvement (PPI) in the Academic Health Science Network (AHSN)**”.

This information sheet describes the research and what participating in it will involve. Please read this sheet, ask any questions you have, and discuss it with the researcher or other people. Please let the researcher know if there is anything that is unclear or anything you wish to know that is not described.

### What is the purpose of this research?

This research will aim to understand how public involvement is working at the AHSN. This will mean looking at the way public members are selected, how and when they are involved, how their involvement is supported, the things that help and hinder their involvement and what things have changed as a result of their involvement. The study is due to be completed and written up by October 2017.

### Why have I been chosen?

As someone working on [project name] with the AHSN, you are being asked to participate. Other people who will be invited to participate in this research will include public contributors and other staff involved in AHSN projects where public involvement is being used.

### Do I have to take part?

You decide whether to take part in this research or not. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part, you can stop at any time. You will not have to give a reason.

### What will happen to me if I take part and what do I have to do?

If you decide to take part, then the research will take two forms: interviews and observation (of internal meetings).

1) Interviews - if you decide to take part, then the researcher will arrange to meet you, at a time and in a place that is acceptable to you. The meeting should last for approximately one hour and will involve you and the researcher discussing your experiences of public involvement. The researcher will make an audio recording of your meeting. After the first meeting, the researcher may want to contact you to request a follow up meeting, if you agree then the researcher will discuss with you the location, time and duration of the second meeting.

2) Observation – if you decide to take part, and providing the other meeting attendees consent, then the researcher will attend meetings as an observer and will take notes and will make audio recordings of the meetings and take notes relating to how PPI is working.

### What are the possible disadvantages and risks of taking part?

The only foreseen disadvantage is that you will be asked to give up an hour of your time to meet with the researcher.

### What are the possible benefits of taking part?

Your participation will contribute to our understanding of the way public involvement is working at the AHSN.

### What if something goes wrong?

If you have any complaints regarding the handling of the research you may contact the researcher’s academic supervisor, [contact details]

### Will my taking part in the research be kept confidential?

All information collected from you will have your name, address, and work place removed so that you cannot be recognised from it. Any data stored will be in accordance with the Data Protection Act.

**What will happen to the results of the research?**

The aim is to produce a final report that will be available from the University web site. The information may be shared at conferences and publications may be produced. No identification of persons will be made in any publications following the study, unless express permission is granted.

**Who is organising and funding the research?**

This research is being funded by the AHSN, and the researcher is undertaking the research as part of a PhD course at the [University name].

If you have any questions about this research, please contact the researcher, [researcher name and contact details].

This information sheet is for you to keep and you will be given a copy of the signed consent form. Thank you for considering participating in this study.

=====  
==

## CONSENT FORM

**Title of Project: Evidencing the value of Patient and Public Involvement (PPI) in the Academic Health Science Network (AHSN)**

Name of Researcher: [name]

**Please initial box**

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

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

3. I agree to take part in the above research.

4. I agree to be contacted for interview and to this being audiotaped. If I withdraw consent, then my interview responses will not be stored or used.





## Appendix 7 – ethics approval

[University name and address]

UWE REC REF No: HAS/15/04/145

28<sup>th</sup> April 2015

[Researcher name and address]

Dear [Researcher name]

**Application title: Evidencing the value of Patient and Public Involvement in the Academic Health Science Network (AHSN)**

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed with the following conditions:

1. There is no reference to lone working on the risk register. The researcher will hold interviews in locations chosen by the participants. What safeguards will be put in place to protect the researcher?
2. On all the participant information sheets the researcher might consider
  - i) Under possible disadvantages indicating that ‘the only foreseen disadvantage is that you will be asked to give up an hour of your time to meet with the researcher’ that could then lead on to the benefits of contributing to our understanding.
  - ii) The mobile phone number of the researcher: please confirm that this is not a personal phone
  - iii) All the forms indicate that the researcher will attend meetings and take notes. It might be helpful to participants to know why and what you will be taking notes of. At the moment the agreement to ‘being observed’ could make people feel uncomfortable.

[Details on using the university logo, when to notify the ethics committee of changes, closing remarks, and signature].

## Appendix 8 – ethics compliance

ITEM	FROM..	ACTION	Open or closed.
There is no reference to lone working on the risk register. The researcher will hold interviews in locations chosen by the participants. What safeguards will be put in place to protect the researcher?	Ethics Committee approval conditions	The risk register has been updated to show that the researcher will communicate the timing and location of interviews to supervisor, to reduce vulnerability.	Closed
On all the participant information sheets the researcher might consider i) Under possible disadvantages indicating that ‘the only foreseen disadvantage is that you will be asked to give up an hour of your time to meet with the researcher’ that could then lead on to the benefits of contributing to our understanding.	Ethics Committee approval conditions	‘the only foreseen disadvantage is that you will be asked to give up an hour of your time to meet with the researcher’ has been added as a disadvantage to all participant information sheets relating to interviews. 14 May 2015.	Closed
On all the participant information sheets the researcher might consider ii) The mobile phone number of the researcher: please confirm that this is not a personal phone	Ethics Committee approval conditions	It is a personal mobile phone, not linked to the researcher’s address. If there are nuisance calls, the number can be changed. This is seen as low risk. As the condition is for consideration only, no action has been taken. 14 may 2005.	Closed
On all the participant information sheets the researcher might consider iii) All the forms indicate that the researcher will attend meetings and take notes. It might be helpful to participants to know why and what you will be taking notes of. At the moment the agreement to ‘being observed’ could make people	Ethics Committee approval conditions	The phrase ‘will make notes relating to how PPI is working’ has been added to the section on observations on all participant information sheets. 14 May 2014.	Closed

feel uncomfortable.			
Collect hard copy originals of permission forms	Ethics application	Planned.	Closed – see hard copy file
Check that English isn't a 2 <sup>nd</sup> language...and if it is, seek review by public member in similar situation.	Ethics application	If it happens.	Did not apply.
If consent for interview is withdrawn, withdraw data	Ethics application	If it happens.	Did not apply.
If consent for observation withdrawn, do not continue	Ethics application	If it happens.	Did not apply.
Use Project codes	Ethics application	Codes set up – list in hard copy form only.	Assigned and used. Closed
Use Participant codes	Ethics application	Codes set up – list in hard copy form only.	Assigned and used. Closed
Offer participants chance to read the report to check they are happy with the way they are represented	Ethics application	To be done once draft written up.	Closed
Set up strong password protection on laptop	Ethics application	Done. 14 May 2015.	Closed
Check strong password on NAS..	Ethics application	Only access to backup volume on NAS is via Time Machine via laptop, so protected by same strong password. 14 May 2014	Closed
Keep hard copies in locked filing cabinet in locked office	Ethics application	Lockable box furnished with padlock..	Closed
If moving data, password protect files	Ethics application		Did not apply. Closed.

# Appendix 9 – interview coding extract

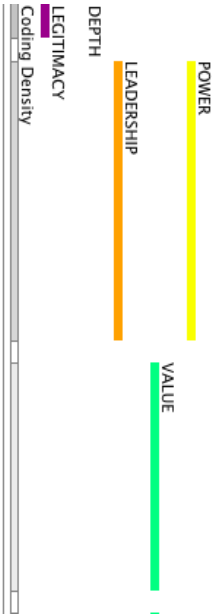
NH31: Yes.

INT: Okay. Erm, and how do you, do you think they have access to decision making, so if there's something that they really did want to challenge, would they really be able to do that?

NH31: I think so. Perhaps not formally but not within the confines of a [P3]. But, but I, I think if they felt very strongly about something that they would find a way to talk to [AHSN COO] or indeed myself around that issue. And clearly we, I would hope we are the type of people who I think would not only listen but take it on board and so something around it. So there may be more informal opportunities to do so if something really kind of got to them or they want to make a point very clearly to us.

INT: Do you think they've change anything outside the meeting? So you've talked about the constructive challenge and the review and the translation, is there anything that's come out of the meeting that you think is different as a result of having public members involved?

NH31: Difficult for me to answer that one because I'm so kind of light touch on, the, err, I wouldn't have the detail around the work streams in the way that [AHSN COO] and others would do. I am kind of on site, but I don't know the realms of it. (Laughter).



## Appendix 10 – observation coding extract

**[00:00:00 – 00:00:10]**

PC32: Er, I'm [first name,second name], and I'm a Public Contributor.

RES : I'm [first name], we've already done me.

PC31: [first name, second name], Public Contributor.

PAR4: [first name, second name], Deputy Director of Nursing at [local service].

**[00:12:26 – 00:13:28]**

NH31: Okay. [PM31, first name] first, and then I would like to have a ...

PC32: I was just going to ... A quick comment: there's a really interesting article – in, I think, last week's Nursing Standard – about falls and, um ... I think it's from a ... Can't recall exactly where the Acute Trust – up North, somewhere – but they've managed to reduce falls. A lot of the wards can demonstrate no falls over 30 days, or even 60 days, by whatever patient safety technique they're using. So, I mean, if you ... It might be interesting to have a speaker from there and something a bit different?

AH33: Find out, yeah.

PAR4: They've ... That's the safety brief.

PC32: Sorry?

PAR4: That ... I think that's the safety brief.

PC32: Oh, is it?

PAR4: Yeah, yeah.

Coding Density	LEGITIMACY	POWER	PC role – patient advocate	LEADERSHIP
				PC role – Boundary questioner