



Swansea University
Prifysgol Abertawe



Swansea University E-Theses

Constructing the meanings of PPI within local organisations: An ethnographic study in England and Wales.

Scalabrini, Silvia

How to cite:

Scalabrini, Silvia (2013) *Constructing the meanings of PPI within local organisations: An ethnographic study in England and Wales.* thesis, Swansea University.
<http://cronfa.swan.ac.uk/Record/cronfa42599>

Use policy:

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence: copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder. Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

Please link to the metadata record in the Swansea University repository, Cronfa (link given in the citation reference above.)

<http://www.swansea.ac.uk/library/researchsupport/ris-support/>



Swansea University
Prifysgol Abertawe

Constructing the meanings
of PPI within local organisations:
An ethnographic study in England and Wales

Silvia Scalabrini

Thesis submitted to the University of Wales in fulfilment
of the requirements for the Degree of Doctor of Philosophy
College of Human and Health Sciences

2013



ProQuest Number: 10805357

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 10805357

Published by ProQuest LLC (2018). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

SUMMARY

This thesis provides a sociological analysis of the process of the construction of meanings of Patient Public Involvement (PPI) policies within two Local Involvement Networks (LINKs) and two Community Health Councils (CHCs), which were citizen-engagement organisations that formed part of the health care systems of England and Wales. Drawing on symbolic interactionism, the study uses the selected bodies as sites to explore comparatively how frontline actors (such as volunteers, salaried staff and NHS professionals) understood and enacted PPI in everyday work. An ethnographic approach was employed to investigate the interaction and the meaning-making activities of stakeholders in local PPI arenas. The research is based on a combination of observations, semi-structured interviews and documentary analysis undertaken over a period of sixteen months.

The study shows that the meanings of PPI in LINKs and CHCs is shaped by social processes, such as the interplay between informants' understandings of role and everyday relationships between volunteers, officers and NHS professionals in the course of the work. The research suggests that, despite different legislation, Welsh and English informants understood their place in CHCs and LINKs in similar ways by drawing on established working practices and a notion of the ideal volunteer. Volunteers made sense of their role by drawing on images of 'the public', viewed as an imagined community of people with negative attributes against which volunteers constructed the positive meaning of their own role.

Informants in the study understood PPI in multiple ways that evidenced the relevance of the organisational and social context in 'doing involvement'. In discussing how local stakeholders' concerns to comply with the legal requirement 'to do PPI' were translated into practical devices to show evidence that involvement was proceeding, the concept of juridification is used to develop a better understanding of grassroots actors' interpretations of policy.

DECLARATION

This work has not previously been accepted in substance for any degree and is not being currently submitted in candidature for any degree.

Signed.....
Date 15 / 09 / 2014

STATEMENT I

This thesis is the result of my own independent work, except where otherwise stated. Other sources are acknowledged by explicit references. A bibliography is appended.

Signed.....
Date 15 / 09 / 2014

STATEMENT II

I hereby give consent for my dissertation, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed.....
Date 15 / 09 / 2014

ACKNOWLEDGMENTS

This is not 'just' a thesis: it is the result of a process that changed me significantly. By relocating to Britain I experienced great loneliness and suffering, but I also found new Friends, I fell in love with this country and (hopefully) I learnt to forgive myself. So there wouldn't be my Ph.D. thesis (and a very different Silvia either) without the love, the support and the hard work of several people.

I am especially indebted to my supervisors for their incredible commitment to my study. Prof David Hughes provided superb intellectual guidance and spent a great amount of time showing me several ways to do things and to think more sociologically. I couldn't have had a more dedicated and patient supervisor, and he's always done his best to ensure that I could have everything I needed to do the work. Thank you for putting up with the emotional side of my character! I know I've been extremely lucky, and I'm grateful for this opportunity. Dr David Rea provided enthusiasm for the research and useful criticism regarding my taken-for-granted assumptions about symbolic interactionism. Thank you for your encouragement and for being so passionate about my thesis.

In addition, thanks to the insightful comments provided by the external examiner, Professor Robert Dingwall, and by the internal examiner, Professor Lesley Griffiths, which allowed me to improve considerably the final version of the thesis.

I'm also indebted to Professor Guido Giarelli for his wise advice, particularly when I felt totally inadequate and unable to complete the thesis. Thank you because you have always believed in me.

Heartfelt gratitude is due to all the people who have taken part in the study. Thank you for your patience, for sharing your thoughts with me, for answering my numerous questions, for your lifts after a meeting, for welcoming me in your homes. I won't forget you.

None of this would have been possible without the love and the good humour of some friends. Angelica, I wish I had recorded all our Skype calls over the years! At times I've been pathetic, (tragi)comic and boring. But you listened, you told me off when I cried and you understood exactly all my feelings before I could actually work them out. Since there is a copy of your letter in each room of my flat, my days have been easier. You're not my best friend, you're a sister.

Philip, thank you for our endless conversations about everyday meanings, the Scottish devolution, British accents and for your fascinating tales about the North of England. I have learnt so much from you, and thank you for introducing me to your fantastic world. We shared the status of 'foreigner' in Swansea and I'm glad that you

showed me the funny side of it. Thank you for all your help, for listening, for having such a big heart and because you saw through me in ways that surprised me at times.

Alexandra, thank you for your genuine love and for being so close to me when I am pedantic and when I pretend I don't understand. Thank you for caring so much about me and for finding the time to be with me whenever I need your friendship. We deserve a prize for our self-irony!

Didem, thank you for our amazing time in Turkey, for our debates on the famous bench, for your emails and your gifts. I'm looking forward to hug you soon. I know that you've always been in my pocket, and that is where I will always find you.

Simon, I am so glad that we laughed so much! Thank you for understanding my explosive Italianity and thank you for our discussions about our PhDs.

Big love also to Monia, Raffi, Pietro, Pino, Alberto, Audrey, Carolina, Rachel. You've all been there through Skype calls, emails and time spent together. You are all brave people in very different ways, and I am grateful to have you all in my life.

Last but not least, I want to thank my family. I want to thank my aunt Milena and my uncle Gianfranco for supporting me in every decision of my life, for your optimism and for your love.

Although my sister Sara is the youngest in the family, I believe she's always been the leader of us all. Your abilities to negotiate have been invaluable in the history of our family, but also in helping me to understand what I was really doing. Thank you Sara, Mum and Dad for our endless Skype calls, every evening. Thank you for loving me even more when I turned into a horrible person because I wasn't writing in the way I wanted. Thank you for all the parcels with homely food that you regularly sent, for all the letters you wrote, for listening to my ramblings about symbolic interactionism. Thank you for believing in me and for encouraging me to dream. This thesis is also yours.

This Ph.D. was supported by a Collaborative Ph.D. studentship from the Foundation for the Sociology of Health and Illness. The Foundation has also fully-funded my participation at a BSA Medical Sociology conference and it also allowed me to present the findings of my study at an international conference. I am very grateful for the generous financial support received over the years, which allowed me to further my personal development and training.

To my sister Sara, my mum Clelia and my dad Piero
La passione e l'insaziabile curiosita' per il quotidiano sono genetiche.
(Passion and insatiable curiosity for everyday life are genetic)

CONTENTS

SUMMARY	2
DECLARATION AND STATEMENTS	3
ACKNOWLEDGEMENTS	4
DEDICATION	6
CONTENTS PAGE	7
LIST OF ABBREVIATIONS	11
CHAPTER ONE: INTRODUCTION	13
Introduction	13
Genesis of the study	15
Rationale for comparison	16
Description of the study	18
The research questions and methods	19
The roadmap of the thesis	20
Conclusion	23
CHAPTER TWO: BACKGROUND LITERATURE	24
Introduction	24
LINKs and CHCs: some initial definitional uncertainties and their implications	25
The classic tradition of symbolic interactionism	29
The limits of formal organisation	32
The constraints of the institutional environment	34
Qualitative studies of PPI policies	37
Conclusion	40
CHAPTER THREE: RESEARCH METHODOLOGY AND PROCESS	41
Introduction	41
Symbolic interactionism: some methodological considerations	42
The fieldwork process: initial issues	47
Negotiating access	49
Ethnographic work	50
Observations of case studies	50
The experience of observing	52
Data recording	55
Interviews	56
Managing interview data	60
Documents	60
Ethical considerations	61
Data analysis	63
Conclusion	66

CHAPTER FOUR: DESCRIPTIONS OF RESEARCH SETTINGS 67

Introduction	67
CHCs	68
Rainbow City	68
Workplace	69
Staff structure	70
Members	71
Blue City	71
Workplace	72
Staff structure	73
Members	73
LINKs	74
Red LINK	74
Greenshire LINK	74
Workplace	75
Conclusion	76

CHAPTER FIVE: CONSTRUCTING ROLES AND RELATIONSHIPS WITHIN LINKs 77

Introduction	77
Volunteers' motivations for involvement	80
Officers' background	82
Constructing roles and relationships	84
The view from the top	85
United but disjointed: actors' constructions of roles	88
Constructing relationships	101
The ideal model of volunteer	104
The concept of network in PPI	108
Conclusion	112

CHAPTER SIX: CONSTRUCTING ROLES AND RELATIONSHIPS WITHIN CHCs 116

Introduction	116
Volunteers' rationale for involvement	117
Officers' background	118
Constructing roles and relationships	121
The view from the top	121
Officers: building CHCs in their own image	123
Becoming competent members	135
Interpreting the new top-down framework	138
The role of officers in mediating change	140
Conflict and factions	144
Redefining the role of volunteers	151
Conclusion	152

CHAPTER SEVEN: CONSTRUCTIONS OF THE PUBLIC	156
Introduction	156
Imagining the public	158
Who is the public?	169
The public ‘out there’	178
Are there counterpublics?	180
Conclusion	184
CHAPTER EIGHT: UNDERSTANDING PPI: RULES, EXPECTATIONS AND INTERPRETATIONS	187
Introduction	187
Legal provisions regarding PPI for LINKs and CHCs	188
The role of LINK development workers and CHC PPE officers	192
Learning about PPI	195
Defining PPI: volunteers’ and officers’ views	200
Professionals’ views of PPI	208
Conclusion	211
CHAPTER NINE: ‘DOING PPI’ AND SHAPING POLICY	213
Introduction	213
‘Doing PPI’: everyday work of officers within LINKs and CHCs	214
‘Doing PPI’: the role of volunteers	221
‘Doing PPI’: negotiations within the NHS and LA	235
Understanding the practices of PPI in the NHS	236
Sustaining relationships with the NHS	243
PPI in the LA	248
Juridification	251
Conclusion	253
CHAPTER TEN: CONCLUSION	255
Introduction	255
The policy and statutory frameworks for LINKs and CHCs: how front-line actors responded to top-down messages	255
Everyday practices of PPI in local arenas	258
“We have to do it”: the juridification of PPI	259
Sociological contributions	259
Policy implications	263
Critical evaluation of the thesis	267
Suggestions for further research	269
Conclusion	270

REFERENCES	271
APPENDIX ONE: TABLE WITH PARTICIPANTS' PSEUDONYMS	301
APPENDIX TWO: INFORMATION SHEET	303
APPENDIX THREE: CONSENT FORM	305
APPENDIX FOUR: ETHICAL ISSUES	306

LIST OF ABBREVIATIONS

AGM	Annual General Meeting
BME	Black Minority Ethnic
BSA	British Sociological Association
CCG	Clinical Commissioning Group
CHC	Community Health Council
CO	Chief Officer
CQC	Care Quality Commission
CRB	Criminal Record Bureau
CST	Critical Social Theory
DH	Department of Health
EC	Executive Committee
GP	General Practitioner
HA	Health Authority
IRAS	Integrated Research Application System
LA	Local Authority
LC	Local Committee
LHW	Local Healthwatch
LHB	Local Health Board
LHU	Local Health Unit
LINK	Local Involvement Network
LGBT	Lesbian Gay Bisexual Transgender
MAC	Mixed Advisory Committee
NAS	National Autistic Society
NHS	National Health Service
ONS	Office for National Statistics
PA	Personal assistant
PCT	Primary Care Trust
PPI	Patient Public Involvement

PPE	Patient Public Engagement
PPI	Patient Public Involvement
Forum	Forum
PRG	Public Reference Group
REC	Research Ethics Committee
SHA	Strategic Health Authority
SSN	Sistema Sanitario Nazionale
SO	Support Organisation
UK	United Kingdom
WAG	Welsh Assembly Government
WG	Welsh Government

CHAPTER ONE

INTRODUCTION

Introduction

Patient and public involvement (PPI) policies have been adopted in a variety of healthcare systems around the world with the intention of increasing the involvement of a range of stakeholders in a variety of ways and a variety of settings. Examples are numerous. The Italian region Emilia-Romagna recommended the establishment of Mixed Advisory Committees (MACs) in 1994 as a way to enable ordinary citizens to express their views on health care services (Giarelli, 2009; Serapioni & Duxbury, 2012). In the Netherlands, a neo-corporatist approach provides virtually all patients' organisations with institutional opportunities to be involved in decision-making processes (van de Bovenkamp & Trappenburg, 2009), whereas in Germany patient participation develops along three levels - macro, meso and micro - at which actors may advise respectively on the regulation of care, promote information about health-related decisions and foster collaboration with professionals in individual consultations (Loh, Simon, Bieber, Heich, & Härter 2007). Further afield, in Canada there are several regional initiatives that involve patients and members of the public in discussions about a number of health-related topics (Contandriopoulos, 2004; Lehoux, Daudelin, & Abelson, 2012), while the Consumers Health Forum of Australia advocates to represent the interests of healthcare consumers.

The United Kingdom (UK) has a long history of involvement in healthcare, which is probably the reason why it is considered a leading country in the field (Tritter, 2011). In the early 1970s, statutory citizen-engagement organisations were introduced in the UK National Health Service (NHS) as a way to include patients and the public views in the healthcare system. Community Health Councils (CHCs) were established in England and Wales in 1974 and Local Health Councils were set up in Scotland in 1975 (Bochel & MacLaran, 1979), while Health and Social Services Council became operational in Northern Ireland only in 1991 (Carlyle, 2012). Since then, the British system of PPI has been subject to various significant organizational reforms. Notably, England and Wales ceased to share common PPI arrangements in 2003,

when Patient and Public Involvement Forums (PPI Forums) replaced the English CHCs. In 2008, Local Involvement Networks (LINKs) were introduced following the abolition of PPI Forums (Vincent-Jones, Hughes, & Mullen, 2009); for the first time, the new bodies were also responsible for monitoring social care services. Lastly, the Coalition government announced that LINKs would evolve into Local Healthwatch (LHW) in 2010 (Tritter & Koivusalo, 2013), a reform that became operational in April 2013. On the other hand, Wales retained CHCs and expanded their role in 2004: since then, CHCs have experienced a period of stability until the reorganisation in 2010 (see Chapter Two and Four).

Just as PPI arrangements are strikingly diverse, so there are several distinct ways of conceptualising the meanings of involvement in healthcare. By confining the analysis to the UK nations, it will be instructive to highlight the extent of variation in the terminology used. For instance, the NHS Confederation (2011) published a discussion paper examining *Patient and Public Engagement* (PPE) in Clinical Commissioning Groups (CCGs), while the NHS Future Forum (2011) reported on *Patient Involvement and Public Accountability* in relation to the Coalition government's plans to reform the English NHS. Across the border, the Welsh NHS Confederation created a web-based learning guide to support Local Health Boards (LHBs) in meeting statutory requirements, which uses the language of *citizen engagement and involvement* to present the Welsh Government's policy in this area. A collection of research reports is also presented on this online platform, which explores themes such as *Community Engagement and Community Empowerment* (The Welsh NHS Confederation, n.d.). Elsewhere in the UK, Northern Ireland has embraced the concept of *Personal and Public Involvement* (PPI) (Public Health Agency, 2012), whereas Scotland has adopted the notion of *Patient Focus Public Involvement* (PFPI) (NHS National Services Scotland, 2010).

The wide, and often confusing, variety of terms employed in policy documents on PPI raises the question of how involved stakeholders at grassroots level understand policies coming from the central government, how they develop meanings in-use of involvement and how they act upon them in everyday experiences of involvement. My interest in the field emerged *inter alia* from the realisation that local participants (such as volunteers, NHS professionals, paid staff facilitating participation, and

voluntary organisations) interact in local arenas 'to do PPI' by making practical decisions that shape - and in turn are shaped by - the forms of involvement. In this thesis, policy implementation is viewed as an active process in which interactions between participants shape meanings and enactments of PPI within certain organisational arrangements and institutional frameworks regulating involvement. In light of the varying definitions of what PPI involves and a background of uncertainty about how PPI arrangements work in practice, there is a need to investigate empirically PPI policies "in the making" (Prus, 2003, p.13) by exploring the meanings that participants attach to involvement and how they develop them in interaction within certain social and organisational contexts.

I will use the term PPI as an academic definition to provide a consistent terminology throughout the thesis. In effect the study aims to explore the processes via which informants made sense of the policy and implemented it, rather than developing particular definitions of experiences of involvement. However, I will highlight the use of other terms (such as Patient and Public Engagement or simply engagement) as a commitment to respect participants' choices in everyday language.

Genesis of the study

The motivation for choosing PPI policies as a topic for investigation originated from my professional experiences in 2007. Before starting my Ph.D. in October 2009 I worked as a research assistant in Italy for three years. One of the two projects I was working on at the time was concerned with patients' experiences of health care services within a Local Health Unit (LHU), the Italian equivalent of a Welsh Local Health Board (LHB) or an English Primary Care Trust (PCT). The study, which lasted for twelve months, was funded by a private foundation and commissioned by the local MAC. It focused specifically on first-time mothers and people who had undergone colorectal screening tests. My role was to conduct interviews and focus groups with patients and write a final report on the overall findings, with particular attention to patients' access to services and obstacles encountered in using services. The participants recruited were genuinely – and impressively – enthusiastic about sharing their views of their service experiences. After analysing the data and

presenting the report to the MAC, I was asked to attend a private meeting with the Director of the LHU and a senior manager responsible for health promotion, who was also my supervisor throughout the study. The Director expressed his concerns about the inclusion of certain patients' quotes in the report, which highlighted some issues in the patient-doctor relationship and appeared to indicate general problems with access in one specific service area. He believed that professionals would not accept criticism emerging within service users' accounts, and suggested that he would reformulate my report and personally negotiate some of the doctor-related issues mentioned by research informants. After that meeting my contract came to an end and I am not aware of whether, or how, the Director and other professionals eventually acted upon my report. At the time I felt disappointed in my colleagues and also that we were failing to acknowledge the contributions of patients who had generously donated their time to share their experiences; it seemed to me that this was a missed opportunity to improve further the general high quality of the services provided in the area by discouraging open dialogue.

This experience led me to look abroad to seek other forms of public involvement. I was still keen to explore other forms of participation in different social and legislative contexts, and therefore began to identify countries that had formalised arrangements for facilitating participation. At the same time I made the decision to undertake a doctorate; based on these interests, I identified PPI in UK health care as a possible research site. I then approached a potential supervisor at Swansea University in Wales to enquire about applying for a position as a doctoral student and whether he would be available to supervise me in case of a positive response, and decided to apply for a place there. After a successful interview in June 2009, I relocated to Wales to start my doctorate.

Rationale for comparison

The idea for this study developed largely from my supervisor's work on UK devolution policies, PPI and patient choice. The original idea for this study was a single case study approach focused on Wales and enactments of PPI arrangements within CHCs. As such, the main research question I proposed to address was: 'Why

is Wales especially interesting?' The idea of focusing on Wales was mainly dictated by the need to control travel costs against the background of my limited research funding. However, in the course of discussion with my supervisor we came to the conclusion that a comparative study examining PPI policies in England and Wales would make a stronger and more interesting study. As a result the comparative framework became a key aspect of the proposal. This was partly due to the fact that, after the creation of a devolved Welsh Assembly in 2006, England and Wales were pursuing increasingly divergent health policies, particularly in relation to the role of markets and competition. A comparative study would thus make it possible to address the question of whether interpretations or enactments of particular PPI arrangements (i.e. understandings of what PPI means) were related to wider healthcare policies and statutory frameworks.

My aims in selecting CHCs and LINKs as sites to explore social constructions of meanings of PPI policies were as follows. Despite a number of studies examining patients and professionals interacting in various settings, such as the charity HEART UK (Weiner, 2009) or the NHS Foundation trusts (Allen et al., 2012), to the best of my knowledge, nobody has explored PPI through a comparison of the work of Welsh CHCs and English LINKs. The thesis thus addresses this gap by offering a unique insight into the practices of involvement in two countries that shared common institutional arrangements for about thirty years, but are now taking different paths. I thus combined the desire to make an empirically informed sociological contribution to the analysis of the practical construction of PPI policies in interaction, with an interest in the operation of citizen-engagement organisations that, so far, have received little attention.

Although one CHC and one LINK would probably have been sufficient for a doctoral study, it was decided that two organisations should be examined in each country in order to provide an insight into how organisations dealt with the unique social contexts and geographical characteristics of different regions in the same country. I shall discuss the rationale underlying the selection of the particular CHCs and LINKs included in this study in Chapter Three.

Description of the study

This thesis examines comparatively the process of construction of the meanings of PPI policies in two LINKs and two CHCs. It aims to explore whether local understandings of the concept shape everyday practices of involvement, and how the statutory frameworks of the countries are interpreted, and acted upon, at grassroots level. In addressing these empirical issues, I have concentrated on involved stakeholders (such as volunteers, paid members of staff and professionals) and their interactions in local arenas in which they make sense of and enact PPI policies.

To do so, symbolic interactionism (Blumer, 1969) was considered to be the most appropriate theoretical perspective to investigate PPI from frontline actors' point of view by taking into account bottom-up experiences and issues encountered in everyday work. The study focuses particularly on how the meanings of PPI were formed in social interactions. Given my strong sociological interest in the pragmatic aspects of policy, an interactionist approach is particularly valuable in exploring PPI in action. The institutional frameworks regulating involvement and organisational arrangements are viewed as contexts of interaction framing the processes of meaning creation. Notably, the thesis can be seen as an attempt to apply symbolic interactionism to an area of pragmatic policy interest by showing its value in examining the organisational processes through which the meanings in use of the policy are created and shaped in interaction. The rationale for using symbolic interactionism and the selected methods are discussed in-depth in Chapter Two and Three.

Furthermore, both LINKs and CHCs appeared to be bodies with fairly open boundaries that 'bridged' a variety of organisations broadly involved in the field of health and social care locally. This may be considered a new area of investigation which indeed deserves special attention. Thus the thesis sets out to apply symbolic interactionist theory to an important area for applied research, and also – and to a modest degree – to provide some new insights about the working of bodies, lying somewhere on the continuum between organisations in their own right and looser

networks, which are operated mainly by volunteers and are open to the general 'public' (see Chapter Two).

Ultimately, this thesis is not an evaluation of PPI policies in England and Wales, and does not aim to assess the superiority of LINKs over CHCs or vice versa. The key focus of the empirical study is to illuminate the pragmatic policy consequences and sociological significance of the processes via which actors in LINKs and CHCs construct the meanings of PPI and how these understandings shape their engagement activities.

The research questions and methods

The thesis aims to explore comparatively how frontline actors involved in CHCs and LINKs constructed PPI as they carry out everyday tasks. To do so, the following research questions guided the development of the study:

- 1) What are the perspectives of CHCs/LINKs volunteers and salaried employees, local stakeholders and NHS professionals regarding their roles in PPI?
- 2) How is PPI understood by involved stakeholders, and how far are the meanings of PPI influenced by relationships and interactions between paid staff and volunteers, patients and the public?
- 3) How do understandings of national policy influence the PPI activities undertaken locally?
- 4) Have the different institutional contexts of the two countries resulted in different understandings and approaches at grassroots level?

The identified research questions were developed as an attempt to shed light on LINKs and CHCs' constructions of the meanings of PPI by considering key themes in the interactionist tradition.

The study is based upon qualitative data generated through observations of meetings and interviews with a variety of local stakeholders over a period of sixteen months. Fieldwork was conducted from January 2010 to April 2011. Such a prolonged involvement with informants enabled me to gain deep insights into a variety of topics including how CHCs and LINKs made sense of and responded to significant changes

imposed from above. The former were reorganised into new bodies, which became operational from 1st April 2010, whereas the Coalition government announced the evolution of the latter into LHW in the White Paper “Equity and Excellence: Liberating the NHS” in 2010. The study not only presents understandings of PPI policies “in the making” (Prus, 2003, p.13), but also discusses the uncertainties that local actors (particularly in Wales) encountered in dealing with a new organisational structure while they made sense of and adjusted to new legislation. As such, the findings are timely in that they help to improve understanding of the current state of evolving PPI arrangements in a changing NHS. LHW are gradually becoming operational after LINKs were dissolved in March 2013, while Professor Mark Drakeford, the current Minister for Health and Social Services, welcomed the proposals to strengthen the role of CHCs following the published review of the bodies undertaken by the Welsh Institute for Health and Social Care in 2012. At the time of writing, however, it remains to be seen whether, and how, CHCs will be restructured. As an illustration of the complexity that frontline actors experience at grassroots level, the study findings could thus be of assistance to participants involved in the development of LHW.

The roadmap of the thesis

The thesis is organised as follows.

Chapter Two introduces symbolic interactionism, and its founder Herbert Blumer, as the most appropriate framework for the study by highlighting the importance of negotiations and the exploration of the meanings of involvement activities in everyday contexts. It justifies the reason why, at the onset of the study, I maintained distance from the negotiated order perspective (Strauss, Schatzman, Bucher, Ehrlich, and Sabshin, 1964). It also reviews some relevant literature related to the limits of formal negotiations and the constraints posed by the institutional environment, with particular reference to the notion of juridification (which will be expanded upon in Chapter Nine).

Chapter Three, 'Research Methodology and Process' examines the methodology and methods employed, and justifies the selection of symbolic interactionism as a suitable perspective to answer the research questions. It also discusses the fieldwork experience and offers some reflections on the negotiation of access, the relationships established with informants, ethics and the process of data analysis.

Chapter Four, 'Description of research settings' provides an overview of the social and organisational contexts of the selected LINKs and CHCs.

Chapters Five to Nine discuss the empirical findings by presenting the stories of two CHCs and two LINKs as they enacted PPI policies in local arenas. The chapters analyse the processes through which informants constructed the meanings of involvement. Chapter Five, 'Constructing roles and relationships within LINKs', and Chapter Six, 'Constructing roles and relationships within CHCs', introduce the organisational context of the bodies by discussing the interrelated nature of role constructions and everyday relationships in PPI. These chapters contribute empirically to understand how informants made sense of their role and how those understandings oriented the work of CHCs and LINKs towards particular tasks or areas of interest. The Welsh and the English statutory frameworks imposed different constraints on CHCs and LINKs membership although local actors still had scope for negotiations of roles. Both chapters therefore focus on everyday negotiations of organisational practices by exploring how volunteers and salaried staff constructed insider groups and defined the ideal model of the volunteer role against interpretations of legal provisions and the associated requirements. Chapter Six shows how CHC officers managed to establish trust and personal bonds with members that – albeit at varying degrees in the two bodies both before and after the reorganisation – strengthened working relationships and promoted shared understandings of roles and the core tasks of the organisations. This scenario is compared to the situation of LINKs' and how participants and salaried staff negotiated working relationships based upon contrasting views of their respective roles and conceptions of what the LINKs network arrangement meant. The chapters also explore professionals' views about organisational roles and how those emerged out of their expectations concerning what volunteers and salaried staff might

contribute to the NHS. Chapters Five and Six thus lay the foundation upon which the analysis of the remaining empirical chapters is built.

Chapter Seven, 'Constructions of the public', is an exploration of how CHCs and LINKs develop understandings of 'the public' in everyday practices. Constructions of the public were formulated in opposition to volunteers' self-understandings of the roles of organisational insiders. Volunteers were able to explain their place in CHCs and LINKs with reference to positive personal attributes such as acting in the interest of 'the public' or ability to consider and assess 'wider issues'. But a way of thinking that portrayed volunteers' involvement as a consequence of their positive attributes led to a perception that members of the general public lacked the necessary attributes for full participation, and thus created a symbolic divide between volunteers and the ordinary people whom they serve. Consequently, 'the public' was viewed as an entity 'out there', at a distance from the internal work of the organisation, whose characteristics were related to the insider actors' interpretation of regulations, understandings of organisational roles and local contingencies.

Chapters Eight, 'Understanding PPI: rules, expectations and interpretations', discusses the legislation and the policy documents that frame PPI policies in England and Wales. In addition to identifying key differences, it discusses the role of dedicated officers invested with the responsibility of 'doing PPI' and it analyses learning opportunities about involvement as developed within LINKs and CHCs. The chapter also explores how informants (volunteers, paid officers and NHS professionals) understood PPI and how their conceptions significantly related to self-understandings of role and to views about the organisations' core tasks. The analysis is then developed further to introduce the idea of juridification to illuminate the process of construction of meanings of PPI.

Building on all the previous chapters, Chapters Nine, 'Doing PPI and shaping policy', examines the practices of involvement in the everyday work of LINKs and CHCs. In particular, I examine employed staff and volunteers' constructions of roles in relation to PPI and how these drew upon symbolic resources (such as images of the public), self-understandings of roles and practical contingencies. The chapter examines how the concept of juridification can complement the key themes emerging

from symbolic interactionist theory to enrich understanding of the processes through which the meanings of PPI are shaped. The findings show that informants focused mainly on the legal dimensions of PPI, rather than alternative aspects that could provide different working understandings of the concept.

Lastly, Chapter Ten discusses the findings and how they answered the research questions of the thesis. In addition, it examines the sociological contribution of the research and it makes tentative suggestions for policy-makers; it also provides a critical evaluation of the study. Lastly, it offers some ideas for future lines of enquiry.

Conclusion

This opening chapter has framed the context of the thesis by discussing increasing prominence of PPI policies in developed healthcare systems and by highlighting the conceptual diversity of top-down ideas on involvement and associated formal arrangements. LINKs and CHCs were introduced as appropriate cases through which to explore constructions of PPI in the UK context. The chapter set out the research questions that guided the research and introduced symbolic interactionism and ethnography as the appropriate approaches to carry out the study. Before turning to provide a detailed account of the research process, Chapter Two presents an overview of symbolic interactionism and its distinctive approach to studying group life and organisational settings.

CHAPTER TWO

BACKGROUND LITERATURE

Introduction

Before exploring the interactional components of doing PPI within citizen-engagement bodies, it is deemed essential to provide an introduction to academic debates that frame the complex concepts and the topics under discussion. Thus the chapter sets the context for the study of the actions and interactions of participants within the selected CHCs and LINKs in the attempt to frame the empirical findings presented in the thesis. It reviews relevant academic literature on symbolic interactionism as applied to public participation activities in the health domain. In doing that, it argues for the value of an interactionist perspective for investigating social policy issues, in particular by exploring how meanings of concept such as PPI are constructed in everyday contexts. The chapter summarises some key aspects of the symbolic interaction perspective and its approach to the analysis of group life and organisational settings. It makes the case for the relevance of Herbert Blumer's (1969a; 1969b; 2004) classic approach to social interaction, joint action and collective behaviour to the work of LINKs and CHCs, while also discussing the more recent symbolic interactionist writing on the 'negotiated order' of organisations (Strauss, Schatzman, Bucher, Ehrlich, and Sabshin, 1964), the limits of negotiation and the significance of context and institutionalisation. The chapter explores the extent to which the institutional environment narrows the margins for negotiations and autonomous actions within everyday settings, of which statutory requirements constitute a powerful instance. In particular, I will attempt to relate these aspects to participants' perspectives on the degree of structure and guidance that they believed existed when they tried to make sense of PPI policies, but also to what I found to be the fundamental influence of one type of external constraint, the statutory framework, which I examine extensively in Chapter Nine when I discuss the concept of juridification. Lastly, the chapter also offers an overview of relevant qualitative

studies of PPI that have been broadly informed by micro-related approaches in order to show how my study addresses existing gaps in the literature.

LINKs and CHCs: some initial definitional uncertainties and their implications

The tendency of American Sociology to characterise symbolic interactionism in terms of its alleged social-psychological, micro-level and non-social structural orientation has obscured the fact that a significant number of interactionist studies have been based within or involved analysis of formal organisations (Maines, 2001; Hall, 1987, 1995, 1997; Hall and McGinty, 2002). The low visibility of this strand of interactionist work may partly be explained by a failure to connect what is quite a large corpus of organisational ethnographies with a smaller body of symbolic interactionism writing on organisational dynamics and processes (see McGinty, 2014; Strong and Dingwall, 1983). Additionally the language employed and the focus on organisational process as opposed to structure meant that this research was never assimilated into mainstream organisational sociology (Abbott, 2009: 2). Over time though, symbolic interactionist writers have provided valuable insights on topics such as organisations as systems of meanings (Fine, 1996), the dynamics of organisational negotiation and constraint (Stevens, 2014), and possible convergence with the new institutional sociology (Sandstrom, Martin, and Fine, 2001).

As a neophyte researcher embarking on doctoral research I had to consider how this newer body of symbolic interactionism work on organisations fitted with the classic texts on social interaction and collective behaviour that I was also reviewing, and which parts of the literature would be most relevant for my study. As the reader will see as the thesis progresses, I have elected to base much of my analysis on the classic approach of Herbert Blumer (1969a) and the neo-Chicagoan sociologists closely associated with his approach, and to draw only selectively on the later organisational studies, and my first task in this chapter is to explain why I have aligned myself so closely with the Blumerian perspective.

Although I was aware of some of the writing on organisations, at the onset of the study it was unclear (for reasons that have remained valid in light of the findings

presented) whether organisational analysis could be applied appropriately to LINKs and CHCs. Both appeared to be bodies with open or permeable boundaries, to the extent that they were perhaps not so much organisations *per se* as entities that connected a variety of organisations at the local level. In other words, I was unsure whether engagement fora might be seen as arenas for the creation of collective representations, as manifestations of social movements or as organisations interacting primarily with other organisations. The way LINKs were constituted raised immediate questions since they were explicitly established as ‘networks’ located in a ‘host organisation’ – usually a local voluntary agency (DH, 2006, 2007, 2008). Indeed the policy intention had been to create bodies that by design were different from hierarchical bureaucratic organisations (Martin, 2009), such as their predecessor PPI Forums and CHCs. Additionally, the personnel structure of LINKs and CHCs added further complexity to my reflections because both bodies were split between a small core of paid staff¹ and a larger pool of volunteers, with additional occasional participants drawn from the general public or other local statutory or voluntary organisations. Against this one must allow that, insofar as LINKs and CHCs were bodies established by statute with a clear legal identity, they might be viewed as organisations in their own right, but it seemed to me that definitions remained ambiguous and would depend to a large extent on how participants oriented to these bodies.

Volunteering in organisational contexts has attracted little attention from sociologists (for exceptions, see Otdam, 1979; Gora and Nemerowicz, 1991). Nelsen and Barley (1979) investigated what happened when paid staff and volunteers worked together in a US Emergency Medical Service (EMS). They found that, despite identical training, full-time staff had constructed different occupational identities and had different perceptions of the work. Professional Emergency Medical Technicians had fashioned an “ideology of practice by which they regularly distinguished themselves from volunteers [based on] a set of oppositions that enabled paid EMTs to appropriate the identity of experts while portraying volunteers as amateurs” (p. 631).

¹ LINKs’ members of staff were employed by a host organisation, which usually was a local voluntary organisation, rather than by the LINK itself. The details of the specific organisational arrangements will be discussed in Chapter Five.

Interestingly, these writers set their study in the context of fledgling occupations and the transition from unpaid to paid work. As they state:

Collective tasks once performed by members of a community as a social obligation constitute another source of occupations rooted in unpaid work. In the not too distant past, elder care and support for the needy were the responsibility of extended families, neighbourhoods, and the congregations of churches. Today, people in need of such assistance increasingly turn to social workers, home health aides, and members of other occupations. (1979, p.622)

However, this process contrasts with the situation described in this thesis where it would seem almost a contraction in terms for public engagement bodies representing local communities to become institutionalised or bureaucratized to the extent that paid work replaced informal lay participation. It seems infeasible that more than a small core of paid support workers would ever emerge, though arguably informal participation becomes more formal when some regular participants (as in the case of CHC members) receive expenses.

Thus in the early days of my doctoral studies I was inclined to conceptualise CHCs and LINKs as entities that allowed individuals and organisations to come together to engage in activities that may be variously defined as participation, engagement or involvement in the running of local health services. In particular, I felt that it was crucial to avoid the assumption that participants' perspectives were shaped by their organisational membership. I was aware of Blumer's (1969b) classic analysis of the four stages of social movements in terms of 'social ferment', 'popular excitement', 'formalisation' and 'institutionalisation', and was open to the possibility that collective action involving individuals and community representatives in the health domain was not yet formed under an institutional structure². Furthermore, I wanted

² In the event I did not apply the 'stages' framework. This was partly for the pragmatic reason that I realised my fieldwork period would be too short to observe progression through the stages, but also because I came to have doubts about whether engagement was driven from the bottom up via a grass-roots social movement. My findings suggest that it is top-down policy and the requirements of the legal framework that more powerfully shapes the nature of PPI, as opposed to participants' own efforts to develop the concept in innovative ways.

to allow the possibility that individual actions would often be influenced by individual dispositions rather than by stakeholders' organisational affiliation. For these reasons I decided to adopt a more general Blumerian (1969a; 1969b; 2004) perspective on the basis that his work of symbolic interaction, joint action and collective behaviour provided a way to study the emergence of 'collective definitions', that would remain applicable whether or not the organisational identity of LINKs and CHCs proved to be important. As will be discussed later in the chapter, although this choice may be viewed as side-stepping a significant amount of more recent literature, Blumer's work offers a well-established perspective on social processes, negotiations and joint action that is surprisingly modern in its overall thrust.

I did not wish to dismiss the more recent interactionist organisational literature entirely, but wished to be selective in my borrowings. It seemed to me that were I to be drawn into recent debates about, for example, the internal disagreements within interactionism or the overlap with new institutional sociology, I risked drifting off course. However, although I have maintained a distance from the negotiated order perspective as applied to organisations it became clear, as I progressed with my fieldwork, that two issues from this body of literature were relevant. The first concerned doubts about the extent to which meanings were in fact subject to continual negotiation in the light of arguments and findings from critics within symbolic interactionism who argued that some situations might be shaped more by institutional constraints and stable shared meanings. The second involved the distinction between formal and informal social organisations and the significance of institutions and institutional rules – something that emerged as a key aspect informing the overall development of the analysis.

In the next section I will go over some of this ground in more detail by rehearsing the key arguments of classic symbolic interactionism, and setting out the reasons why symbolic interactionism is an appropriate framework for study collective definitions and the construction of meanings in LINKs and CHCs. In later sections I will then turn to the arguments of the negotiated order perspective and its critics, and the

issues of the limits of negotiation and importance of institutional context – particularly the legal framework – that I want to import into my analysis.

The classic tradition of symbolic interactionism

The aim of this study is to explore local stakeholders' interactions involved in the process of PPI planning and implementation against a background of definitional uncertainty about what PPI means (as discussed in Chapter One). To do so, it is necessary to examine the bottom-up contributions of actors to the shaping of policy as they construct the meanings of PPI and make practical decisions about what it involves in everyday contexts. The research questions as outlined in Chapter One did not lend themselves to a quantitative approach: I had no hypotheses to test, and was doubtful about the value of constructing a questionnaire incorporating some ideal-typical definition of PPI which could be checked against respondents' responses. It seemed to me that a statistical analysis of the proportions of subjects preferring one predefined category to another would be unlikely to get close to the real-world conceptions of PPI recognised by those working in CHCs and LINKs. From background reading of the literature it seemed to me that PPI was a multifaceted – and probably often a confused and contested – concept that would need to be explored by examining how people used the notion in real situations. Consequently I decided that PPI could be investigated by focusing on social processes in order to “show us everyday life brought into being” (Dingwall, 1997, p.61).

Thus, in line with much research concerned with the construction of meanings and social processes, the methodological framework of this study is qualitative and interpretative. I believe that the meanings of PPI emerge in an on-going process of interaction between involved stakeholders and are shaped by on-going negotiations and practical contingencies of work. This fits closely with symbolic interactionism's traditional emphasis on the study of social processes and the need to explore these via fieldwork that engages directly with subjects as they carry out their work (Plummer, 2000).

According to Blumer (1969a), who is widely credited as the founder of the sociological version of symbolic interactionism, the approach rests on three simple premises:

The first premise is that human beings act toward things on the basis of the meanings that things have for them [...] The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellow. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (p.2)

Interpretive activities are thus central to this perspective. As Blumer (1969a) asserted:

We can, and I think must, look upon human group life as chiefly a vast interpretative process in which people singly and collectively guide themselves by defining the objects, events and situations which they encounter. (p.132)

If we translate these general principles into the healthcare domain, we can say that symbolic interactionism sees policy implementation as an active endeavour wherein participants shape organisational arrangements whilst acting within certain constraints which are subject to interpretation and of which statutory frameworks represent a relevant example. Prus (2003) encouraged interactionist researchers to consider policy domains as “interactionally accomplished realms of human group life” (p.15), or examples of joint action (Blumer, 1969a). However, some critics have argued that interactionists privilege the micro-interactional level and neglect the macro level or the institutional level as a result. Yet, Maines’ (1988) explored the “misunderstandings and myths” (p.44) surrounding symbolic interactionism that contribute, erroneously, to the “myth of Blumer’s neglect of societal organisation” (p.43). Maines argued against the idea that symbolic interactionism addresses purely micro-sociological issues by presenting the concept of joint action as “the textual evidence” (p.46) that Blumer actually considered subjects’ interactions as the processes through which enduring social institutions are created. The joint actions formed the meanings of – and thus sustained – social organisations and institutions in everyday life. Maines (1988) stated that:

The interactionist perspective for Blumer was designed to help scholars understand human conduct in any arena of social life and at any scale of analysis. And it is absolutely clear that Blumer (1969, p.538) included the manifest analysis of large-scale organisations as a needed and significant undertaking for symbolic interactionist work. (p.51)

Through the concept of joint action, defined by Blumer (1969a) as “a societal organisation of conduct of different acts of diverse participants” (p.17), individuals and organisations are conceptualised as engaged in on-going processes of sense-making that allow them to shape actively the context within which they operate. The concept builds on Mead’s original idea that individual and collective acts rest on processes of ongoing adjustment, and that symbolic interaction is the process which permits this alignment to occur. For Blumer (2004), “joint action is formed by the participants fitting their respective lines of action to each other; and this is done by the participants taking account of each other’s anticipated and actual responses” (p.34-35). Joint action implies that, in general, participants strive to negotiate and construct shared meanings. The joint act is a social act via which participants come together to interpret, define, and align their actions and arrive at a shared understanding of events. Individual actions must be aligned with other action within the group and also the broader social context. Structure - in terms of social roles, status positions, institutions, social codes and norms - remains important in Blumer’s theory, but only insofar as they enter into the process of interpretation and shared definition via which joint actions are formed. As Blumer (1962) stated:

People [...] do not act towards culture, social structure or the like; they act towards situations. Social organisation enters into action only to the extent to which it shapes situations in which people act, and to the extent to which it supplies fixed sets of symbols which people use in interpreting their situations. (p.190)

According to Blumer interpretation opens a space for agency and innovation within the framework of norms and rules built up; even within these constraints “uncharted and unprescribed lines of development” are possible (Blumer 2004: 36)

Joint actions are an aspect of Blumer's analysis of larger scale collective behaviour. Collective behaviour according to Blumer (1969b) "is concerned in studying the ways by which a new social order comes into existence" (p.169). It involves social processes that may lead to changed perceptions and new social norms. For the purposes of my thesis it is not Blumer's work on crowd behaviour and 'inter-stimulation' that is relevant, but rather his reflections on 'collective definitions'. In Blumer's (1971) discussion of social problems he shows that these "are fundamentally products of a process of collective definition" (p.298).

A social problem, Blumer (1971) writes, "is always a focal point for the operation of divergent and conflicting interests, intentions, and objectives. It is the interplay of these interests and objectives that constitutes the way in which a society deals with any one of its social problems" (p.301). We may extrapolate to suggest that the issues and problems that arise in the field of PPI, and the work of LINKs and CHCs are also subject to such interplay. In the various official and non-official formulations of PPI policies and the discourses of participants in national and local engagement forums, we may expect that both collective definitions with somewhat wider currency and the situated definitions of front-line participants in particular everyday situations enter the picture. Let us move on to consider how more recent symbolic interactionist writing can help us to develop the classic Blumerian analysis.

The limits of formal organisation

The negotiated order perspective can be regarded as one of Strauss' most critical contribution to the field of sociology (Dingwall and Strong, 1985). The approach was developed while Strauss et al. (1964) were exploring comparatively the complex set of relationships occurring amongst patient, clinicians, nurses and other involved professionals within two North American psychiatric hospitals. The negotiated order perspective reconciles the micro-macro distinction in the study of organisations (Stevens, 2014) and suggests that social order was constantly in the process of being negotiated amongst stakeholders concerned. The scholars also suggest that a narrow focus on existing organisational structures and regulations may obscure the significant roles of actors in shaping the social order of organisations. Strauss et al.

(1964) employ vivid imagery and rhetoric to convey the key message of the negotiated order perspective:

The realm of rules could then be usefully pictured as a tiny island of structured stability around which swirled and beat a vast ocean of negotiation. But we could push the metaphor further and assert what is already implicit in our discussion: that there is only vast ocean. (p.313)

However, critics from both outside the symbolic interactionism tradition (Benson, 1977; Day and Day, 1977; Clegg and Dunkerley, 1980) and inside it (Lofland, 1970; Maines, 1977; Dingwall and Strong, 1985) argued that the theory exaggerated the scope of negotiation, while giving insufficient attention to context and constraint. In particular there were concerns that Strauss et al. (1964) had backtracked from the more balanced position of Blumer to deny that organisational structure and institutions had any significant influence. They suggested that there is much more structure than “a tiny island” (Strauss et al., 1964, p.313) of stability and they also contested the idea that everything must be continually negotiable. Dingwall and Strong (1985, p.222) make a particularly important point when they point to the importance of the external accountability of many public agencies to government or other regulatory authorities, and the framework of law, guidance and rules within which such an agency must operate.

Empirical studies, even those by writers sympathetic to the negotiated order perspective, have found that the institutional and organisational environment does impose constraints and patterns of interaction that cannot be immediately circumscribed by negotiations at the face-to-face work-day level (Cox, 1991; Allen, 1997; Nelsen and Barley, 1997; Bechky, 2006; Nadai and Maeder 2008). Thus Allen (1997; 2001) argues in her study of the nursing/medical interface in a British hospital that organizational structures often reflect historic high-level negotiations. She identifies features of hospital work which inhibited face-to-face inter-occupational negotiations although they may help shape ongoing changes in the division of labour between physicians and nurses. In her view social interaction depends on ongoing

interpretive processes to make sense of ongoing relationships and events, but social order is "continuously accomplished rather than negotiated" (Allen 1997, p.515).

Strauss (1978) conceded some ground to the critics, but put forward a counter-argument which accused some of them of reifying social structure and being too ready to see structural variables as determinative of social action. He modified his earlier theory by introducing the concepts of structural context and negotiation context (Strauss, 1978, p.98-99). The former involves the overall context within which negotiations take place, which will have structural properties associated with the organisational environment and economic framework of which the analyst should be aware. The negotiation context concerns the structural properties which directly affect the course of the particular negotiations – “properties that enter very directly as conditions into the course of the negotiation” (Strauss 1978, p.99). This includes the nature of the negotiation, the participants, timescale, setting and so on. These new concepts were not free of problems, with writers normally sympathetic to interactionism complaining that they were difficult to operationalise (Maines, 1982; O’Toole and O’Toole, 1982), and in the case of structural context that their explanatory power within a qualitative analysis was limited (Starbuck, 1982). It might be argued that the new concepts did not advance theory very far beyond the dictum emerging from Blumer’s work to the effect that symbolic interactionist researchers needed to take account of social structure, but only insofar as they could find direct evidence of the influence of particular structural factors in the interactional settings they were studying. Nevertheless the debates around the limits of negotiation were important in promoting a more general acknowledgement in interactionist work that concern with agency had to be balanced by a clearer acknowledgement of the importance of structure and constraint – something that is carried over into this thesis.

The constraints of the institutional environment

The balance between negotiation and constraint is linked to the second highlighted issue discussed in the negotiated order literature – the significance of the institutional

environment. Institutions narrow the space of autonomy and negotiation within organisational dynamics, and one important aspect of this is organisational rules and regulations. As mentioned above, Dingwall and Strong (1983) write that: “Welfare bureaux, school boards, and health care facilities are the subject of various regulations, orders and directives, as well as of extra-legal advice, circulars, memoranda, or requests from federal, state, or county authorities” (p.222). They state that, although organisations cannot be described solely in terms of their legal form, “there is an enormous difference between saying that such forms are in principle infinitely negotiable and recognizing that they are in practice determinate” (p.218). Dingwall and Strong argue that the analytical task for the sociologist is to study how this sense of determinateness is accomplished by organisational actors – how they go about defining work as being in accord (or in non-compliance) with the framework of law, rules and guidance applying to their domain.

In the case of CHCs and LINKs, the law related to the duty to implement PPI, and the framework of guidance and rules that exist in the shadow of the legislation, acted as powerful constraints recognised by volunteers and paid staff. Also the historical context could be seen as a kind of constraint³. For instance, as will be explored in Chapter Five, Six, Seven, Eight and Nine, the perceived weight of legal requirements in relation to PPI left the bodies with limited opportunities for negotiating innovative forms of engagement, which might capture a wider range of local issues and needs.

In order to shed light on how actors made sense of top-down messages when constructing operative definitions of PPI (and how legal constraints thus played a significant role in shaping participants’ actions as they carried out the work), I will draw upon the notion of juridification, which I will expand upon in Chapter Nine when presenting bottom-up decisions in ‘doing PPI’ and shaping policy.

Juridification is a term originally coined by Habermas (1987, p.357) to describe the process via which central components of the lifeworld, including its values, norms

³ As will be examined in Chapter Five and Six, experienced volunteers were also heavily affected by their past experiences as volunteers within the organisations.

and roles are increasingly regulated by law. For Habermas, juridification went hand-in-hand with the development of European welfare states, and resulted in the legal institutionalisation of social rights in the political system. He suggests that this entails a growth of formal, codified law, either via application of new laws to previously unregulated conduct or increasingly detailed regulation of given areas of conduct over time. However, as Habermas and Gunther Teubner (1987) have argued, the colonisation of the lifeworld by law can have negative as well as positive consequences, both in terms of subsuming other ways of seeing under the legal framework and by damaging alternative forms of social organisation.

Juridification is an ambiguous and multifaceted concept deployed by scholars in several disciplines (Blichner and Molander, 2005). For the purposes of this thesis I strip away the specific connections to critical theory, and define juridification as an increasing preoccupation with legal rules and regulation in a given organisational domain. In line with my interactionist approach, I focus on the orientation of the participants themselves to legal, regulatory or supervisory frameworks as an aspect of their everyday sense making and negotiations concerning the nature of PPI work. Following Blumer's approach to social structures, I regard such institutional constraints as significant only to the extent that they clearly affect the interactions studied and the way the participants interpret those interactions. Dingwall (1988), in arguing that the law has invaded medicine as much as medicine has invaded other disciplines, claimed that:

Rules or laws always have to be applied or interpreted. What they mean is what people do with them. People involved in using laws develop a set of shared understandings about what the law means. We might call this a culture of interpretation. (p.75)

In this thesis, and particularly Chapter Nine I will consider how participants in CHCs and LINKs orient to the framework of statute and guidance regulating PPI and how preoccupation with the legal dimensions may override or limit alternative framings of what PPI is about.

Qualitative studies of PPI policies

The existing literature contains many empirical studies that relate to PPI policies, which, of course, may take a number of forms within a variety of organisations concerned with healthcare.

Some of these studies build on important theoretical publications that have been influential in the field. In 1969, Arnstein published a key paper that laid the foundation for the conceptual development of participation across various fields, outlining a 'ladder' of levels of involvement that has been widely used, as well as criticised (see Tritter & McCallum, 2006). Tritter and McCallum's work has been influential in promoting the idea that, aside from the issue of whether the public gains real decision making power in line with the highest rungs of Arnstein's ladder, deliberation that involves the public may bring significant benefits even when citizen control is absent. Abelson and colleagues (2003) carried out a systematic review of the literature in this field, and discuss some of the key aspects of participation activities. They suggest that what is needed for meaningful deliberation is a clear understanding of stakeholders' roles and the purpose of the involvement exercise. Daykin, Evans, Petsoulas and Sayers (2007) identified key enablers and barriers in undertaking PPI, which should be taken into account in the 'making of the policy' as well as in the evaluation stage. In a similar vein, Rowe and Frewer (2005) sought to address the definitional uncertainties in the broad field of public participation by refining a typology of concepts and ideas in use in current practice that may assist practitioners and researchers in 'doing participation'. Martin (2009) reviewed the challenges and the opportunities that enable or hinder participation and identified the need to bridge policy and practice by ensuring that there is a clear theoretical rationale for the structures in place. Callaghan and Wistow (2006) pointed out that the very indeterminacy of the spaces available for participation in different settings and contexts means that a variety of approaches and channels will be used. They argue that it is the choice of the approach and way in which relationships are structured that are critical for success. Others have also explored the theoretical underpinnings of PPI by addressing historical and contemporary developments of the

policy in view of its topical nature and the ongoing debates in the broader field of public policy (Baggot, 2005; Florin & Dixon, 2004; Forster & Gabe, 2008; Gibson et al., 2012; Martin 2008b; Mullen et al., 2011; Stewart, 2012; Tritter, 2011; Vincent-Jones et al., 2009; Wait & Nolte, 2006).

It remains unclear whether actors at different level share common understandings of PPI or have different perspectives. Rowe and Shepherd (2002) completed a survey of English Primary Care Trusts that appeared to show a high degree of consensus between high level and local actors. These authors suggest that actors at both levels perceive PPI as part of a wider set of changes associated with new public management policies about decentralised governance, and greater service responsiveness and transparency of decision making. But one may suspect that agreement about headline policies may co-exist with differences in views of what detailed policies mean in practice. Martin's (2008a) qualitative study of user involvement in cancer-genetics services found that the discourses surrounding PPI were contentious and related to social position and interest, so that the meanings of PPI was re-interpreted by professionals in the light of their own agendas and projects. Additionally there are indications that, irrespective of how far actors of different types agree in their understandings of PPI, particular actors differ in their willingness to engage in PPI at one level rather than another, for example, saying they would be willing to be involved at the programme level, but not as individuals (Litva et al, 2002).

Qualitative studies of PPI practices in various UK settings span the period from the 1990s to the present and the various institutional arrangements that applied during those years. Pickard (1997) examined the work of CHCs and discussed the future legitimacy of these bodies in the light of changes associated with the internal markets occurring in the NHS at the time. Campbell and McLean's (2002) interview study found that social representations of Afro-Caribbean people functioned to constrain their involvement in local voluntary organisations and community activist networks. Rutter et al. (2004) explored how users and professionals understood involvement in two Mental Health Trusts in England as well as the barriers that stakeholders encountered in everyday practice.

A number of empirical studies zero in on the question of how culture, interaction, discursive practices, and emergent definitions come to shape local understandings or enactments of what involvement and engagement mean. Hodge (2005) studied a local mental health forum by investigating its discursive practices, the spaces these provide for professionals and service users, and how those disempowered users by constraining and limiting the impact of their involvement. The finding that administrators and professionals may effectively control the form participation takes is supported by Martin's (2008a) study mentioned earlier, and also by Williams' research (2004) on a local authority-run project to improve services for older people. The latter examined the discursive strategies used to manage tensions that arose when service users expressed views at odds with the policies put forward by the local authority, and suggests that administrators deployed a range of discursive techniques to defuse opposition. Drawing on Moscovici's "social representations theory", Renedo and Marston (2011) highlighted the crucial role of social and relational dimensions in PPI, with particular reference to the ways in which professionals' understandings of PPI affect the development of participants' identities in local arenas. They investigated the PPI activities of a London-based CLAHRC (Collaboration for Leadership in Applied Health Research) to show that professionals' representations of involved people were plural and contradictory, making it difficult for participants involved to construct identities in their own terms, and pushing them towards compliance with bureaucratic requirements.

There is thus already a substantial body of research on PPI. However, as highlighted in Chapter One, to the best of my knowledge there are no past studies that report on comparative ethnographic research concerning understandings and enactments of PPI in British statutory organisations. My study seeks to address this gap by considering the work of English LINKs and Welsh CHCs. It adds to the literature by exploring public-facing bodies with relatively open boundaries that aim to establish a new set of relationships at the local level.

Conclusion

The chapter has examined some definitional difficulties related to the nature of the bodies involved, which led to a review of some of the literature about organisational studies in order to set the context to the study of organisational interactions within CHCs and LINKs. The chapter also provided a broad overview of the relevant literature of qualitative studies concerned with PPI policies and a variety of organisations and arrangements involved in 'doing' participation in the health domain.

CHAPTER THREE

RESEARCH METHODOLOGY AND PROCESS

Introduction

This chapter outlines some key methodological issues in qualitative research and explains the methodological choices made in the thesis. My research took the form of an ethnographic study, consisting primarily of observations, semi-structured interviews and documents acquired during the course of my fieldwork. In this chapter, I attempt to explore how PPI was constituted locally in an on-going process of interaction between involved stakeholders. Also, I discuss how I sought to maximise confidence in my analysis of the meanings of PPI in local engagement organisations via a careful fieldwork approach; in particular I opted to extend fieldwork over a longer period than is common in doctoral studies (sixteen months), by taking a careful approach to cross-checking and corroborating data, and also by engaging with a wide number of participants. Overall, the chapter provides an account of the research process as a way of giving readers of this thesis a basis for deciding on the credibility of the findings.

Throughout the thesis I use the first person to present an interpretive account of the selected organisations' and actors' stories. I decided to render my interpretive voice visible (Charmaz & Mitchell, 1996) because I believe that I played a crucial role in the unfolding of the study from the initial selection of the topic to the choice of what to include in the final report. All data generated are the result of researcher-informant interactions.

This chapter is organised as follows. First, by drawing on the discussion of symbolic interactionism as presented in Chapter Two, it explains how the perspective is well suited to addressing my research questions. Next, it discusses the research process in terms of negotiation of entry and field relations, and describes the ethnographic fieldwork undertaken in terms of four case studies, each based on a combination of observations, semi-structured interviews and documents. This chapter also outlines

some ethical considerations raised by the study before exploring the process of data analysis and the implications of decisions made during the research process.

Symbolic interactionism: some methodological considerations

In accordance with the interactionist perspective (Athens, 2010) as discussed in Chapter Two, Blumer (1969) advocated the use of the method of naturalistic inquiry. I adopted this method to develop an interactionist analysis of LINKs and CHCs as sites to explore PPI planning and implementation. Naturalistic enquiry focuses on exploration and inspection as tools to examine ‘the obdurate character’ of the empirical world. Exploration involves familiarising oneself with research subjects in order to understand how they define their social world, the issues they encounter in everyday life, how they generate the meanings attached to the objects of that world, and how they draw on emergent interpretations to reassess their social context and sustain on-going interactions. As a result, the process of investigation starts by focusing broadly on people’s lives and then gradually zooms in on specific characteristics that are meaningfully identified by actors. In exploring the social contexts of action, the researcher produces descriptions and conceptualisations of problems on the basis of observed interactions and negotiations developed and guided by informants’ contextually-located meanings-in-use. In inspection, the researcher seeks out “empirical instances” (Blumer, 1969, p.44) that relate to actors’ meanings in order to ensure that these meanings, rather than the researcher’s assumptions or preconceptions, constitute the evidential basis of the study.

Other scholars besides Blumer have discussed the concept of naturalistic inquiry. In line with Blumer’s (1969) idea of ‘being faithful’ to social worlds observed, Polsky (1967) argued that it was preferable to study delinquents in their “natural setting[s]”, as this would “avoid as far as possible any serious disruption of daily routine” and thus provide “a fluid research situation consisting of a series of *natural* events in the life of...subjects” (p.135). Matza (1969) emphasised the principles of loyalty and fidelity as facets of naturalistic inquiry. Similarly, Prus (1987) strongly supported Blumer’s endeavour to portray the social worlds of people as “places” where “we

explore, assess, discover, and learn... [and] gain vital input from those whose worlds we purport to understand” (p.306).

Symbolic interactionism can therefore be seen as a genuine invitation to observe research subjects’ experiences, understand the issues that concern them, and unpack the logic-in-use underlying their practical knowledge (Rock, 2001). In this thesis, I propose to develop the realist strand of symbolic interactionism (which could also be labelled as a form of soft constructivism), which accepts that actors act in social worlds that exists independently of the researcher’s presence. The idea of a ‘world out there’, which has an obdurate existence unaffected by the act of researching it, and of which it is possible to gain a certain degree of knowledge, is a cornerstone of Hammersley’s “subtle realism” (1992). Hammersley proposed this position as an alternative to naïve realism and relativism, noting the dominant role of ethnography (and, implicitly, symbolic interactionism’s methodological recommendations) in providing detailed accounts of actors’ understandings of their social worlds. Ethnographic researchers must accept the existence of an underlying reality in the attempt to provide policy-relevant knowledge of the social worlds being studied. Prus (2008) declared that “symbolic interaction is highly mindful that *reality exists, emerges, takes shape, and is to be understood within the enacted features of human group life*” (p.28). In accordance with Hammersley’s subtle realism, I believe that researchers represent reality (Hammersley, 1992) rather than reproducing it: through reflexivity, the researcher can be reasonably confident that all representations offered are based upon a strong corpus of evidence which can produce sound analysis and interpretations.

This is not to deny that researchers’ beliefs, cultural assumptions and values shape the final representation of the worlds they investigate (Seale 1999). Athens (2010) argues that researchers therefore need to acknowledge their values when they engage in naturalistic research:

Naturalistic inquiry does not separate the operation of values in our everyday lives from their operation in our scientific investigations – values affect all our actions, so that the term value-free research is an oxymoron. Although it is impossible to conduct value-free research, it is possible to conduct nonpartisan naturalistic

research. Unlike so-called 'value-free' research, nonpartisan research is guided by the value of nonpartisanship and, thereby, is not value free. (p.119)

Ethnography is viewed as employing the principles of naturalism to describe what typically occurs in research informants' social worlds. I particularly draw on Hughes' (2012) broad conceptualisation of ethnography, which comprises the combination of observations, interviews and documentary analysis. I consider ethnography as a collection of diversified methods that "flows directly from the organising assumptions of symbolic interactionism itself" (Rock, 2001, p.30). As Prus (1987) stated, "there is absolutely no substitute for first-hand ethnographic research" (p.306).

However, the idea of inferring participants' meanings of a phenomenon, such as PPI, from observations in the field remains controversial in academic debates. It might be argued that first-hand engagement with participants will not automatically give the researcher valid insights into their understandings of the social and cultural contexts of action. Arguably, meanings emerge in particular localised interactions, will change according to the priorities and pressures that apply in particular situations, and may not be constant over time. For some researchers this implies the need to zero in on sense-making and the co-ordination of talk in particular sequences of interaction, often through the formal techniques of conversation analysis or discourse analysis, and raises doubts about traditional ethnographic methods.

In recent years qualitative interview studies, in particular, have been criticised for their assumption that research can access an interior subjectivity, or relatively invariant meanings, which can be collected from interview accounts; and analysed in terms of themes, perspectives or attitudes (Strong and Dingwall, 1989; Atkinson and Silverman, 1997; Dingwall 1997). To some extent this has been carried over into an implicit criticism of older-style fieldnotes-based observational studies, which do not seek to collect and analyse audio recordings of particular interactions, but rather rely on a general sense of what is happening and what events mean to subjects that inevitably involves inference and interpretation on the researcher's part. This has led some to argue that, in light of the inherent problems of accessing meanings that exist inside people's heads, it may be preferable to concentrate on observable practices,

including participants' actions and language acts or discourses, that can be systematically recorded and reproduced for the reader's scrutiny alongside the analysis, as is common in conversation analysis and discourse analysis studies (Silverman, 1998; Miller, 1997). Although this approach undoubtedly has value, my own view is that such focussed studies need to be complemented by wide-ranging ethnographies of the more traditional kind that can investigate a more general research question across multiple settings.

Arguably the 'practices not meanings' argument itself erects an over-simple distinction between what is observable and what is not, ignoring the need for interpretation in the domain of practices as well as the domain of meanings. Blumer himself had made a similar distinction albeit between physical and social phenomena, arguing that observation of the social world was inherently more problematic than observation of the physical world. Hammersley (1989) questions that this is in fact true, writing:

It is not obvious that there is anything about the 'subjective' character of social actions that makes their identification, in principle, any more problematic than the description of physical properties such as mass, magnetism or radioactivity. The properties that we ascribe to physical objects are no more strictly observable than those we assign to people (p.191).

Paradoxically, Hammersley's criticism of Blumer suggests a line of defence for symbolic interactionist ethnography against the 'practices not meanings' argument, because it might be argued that the processes via which we reach a theoretical understanding of practices are not fundamentally different from the processes by which we reach inferences about meanings. Both require making inferences about how observed findings can be combined to arrive at a theoretical understanding of the phenomenon being studied, and in both cases there is a need to support inferences with evidence and make a plausible case that the theoretical understanding is credible.

Blumer (1973) himself was undoubtedly an empiricist:

There is no reason why the investigator who follows the symbolic interactionist approach cannot test his assertions and hypotheses about his empirical world by a careful, continuous examination of that world; his position is no different from that of Darwin or scores of competent ethnographers. (p. 798).

The classic ethnographic approach was very much an attempt to provide a large corpus of data derived a combination of observations, interviews, documents and other sources that would provide a credible basis for the kind of theoretical inferences we are considering. The combination of approaches, according to Becker and Geer (1957), provided a way to move beyond the limitations of interview-based qualitative studies by enhancing opportunities for corroboration, cross checking and seeing how concepts that subjects may mention in interviews are used in real work situations:

The most complete form of the sociological datum, after all, is the form in which the participant observer gathers it: an observation of some social event, the events which precede and follow it, and explanation of its meaning by participants and spectators, before, during, and after its occurrence. Such a datum gives us more information about the event under study than data gathered by any other sociological methods. (p.28)

Becker (1970) recommends collecting a large body of data, including both observations and other kinds of data, and experimenting with a variety of procedures for data collection, unencumbered by rigid procedural rules. He argues that the 'interconnectedness of organisational life', and the need for participants to relate to other participants as well as the researcher, makes it unlikely that the participant observer who remains in the field over a lengthy period will be systematically misled by subjects.

While time spent in the field does not translate in a straightforward way into insight into the subjective worlds of subjects, sustained observations over time do enhance confidence that the researchers have had multiple opportunities to elicit situated accounts from a large number of participants in diverse situations, and will have been able to observe the accounts participants gave each other as well as accounts produced for the researcher. In discussing strategies to construct convincing

ethnographic accounts, Golden-Biddle and Lock (1993) highlighted how researchers' account of their field relationships and experiences helped readers assess the authenticity to their stories. In supporting their argument, the authors draw on three ethnographies (Barley, 1983; Bartunek, 1984; Adler and Adler, 1988) and identify field relationships and the prolonged lengths of stay in the field as indications that the authors got close to the members, and implicitly, gained a good grasp of informants' perspectives. In other seminal accounts presented in the ethnographic literature, such as those of Whyte (1943) and Bosk (1979), sustained observations and deep engagement with research subjects are discussed as strategies that build confidence about the data collected. Of course, it is also paramount to approach data collection rigorously and being able to ensure that the evidence and the information gained come from a wide variety of informants and sources.

Uncertainty and ambiguity are constant factors in social interaction and as such they are fully part of the researchers' experience of fieldwork. Meanings are produced in context, and at one point in time may be shaped by exigencies that are not present in future situations. However, social interaction co-exists with a shared cultural framework, shared symbols, and for most of the time an intention to communicate an understandable perspective to co-interactants. Both participants and researchers handle uncertainty by being careful about the kind of inferences they make, by waiting for confirmatory evidence that their initial interpretations are in line with what participants had in mind, and by correcting co-interactants when they seem to have misunderstood. I will return to discuss how I tried to incorporate these insights into my own analysis in a later section of this chapter on data analysis.

The fieldwork process: initial issues

While I was selecting a methodological approach for this study, I was also navigating issues relating to ethics, selection of potential research sites and negotiating entry, and struggling to understand the prescriptive system regulating health research in the UK. When I worked as a research assistant in Italy, I conducted interviews and observations on Sistema Sanitario Nazionale (SSN, the Italian equivalent of the NHS) premises without facing the daunting prospect of an Integrated Research

Application System (IRAS) application. As part of my research I interviewed senior managers and clinicians in SSN hospitals, and sometimes wandered around wards asking nurses for directions when I was unable to find an informant's office. In the early days of the study, on recounting such experiences, some fellow postgraduate students attempted to explain the ethical issues surrounding health care-related research in the UK and the need for such activities to be regulated. Yet a first look at the IRAS website left me with the impression that this was really a system designed for clinical studies, but I worried about how I could provide the required information considering the qualitative nature of my research. This became a source of anxiety, as I believed that a comparative ethnographic study exploring processes and emerging meanings required a flexible research design.

Additionally, I was not sure whether or how the NHS would play a significant role in my fieldwork. CHCs and LINKs were funded by the WG and DH, but their strength appeared to lie in their relative independence from the NHS. CHC officers were technically NHS staff but were presented as supporting the independent voice of the public, whereas LINKs staff members were actually employed by a local voluntary organisation that was contracted by LAs as a host organisation providing support to volunteers. Although CHCs and LINKs held meetings that were open to members of the general public, I did not intend to interview participants about their experiences as users of health or social care services.

In fact, when my supervisor approached the Manager of the Wales Research Ethics Committee (REC) on my behalf, it turned out that a formal application for ethical approval was not necessary. She explained that the committee was now classifying the majority of studies that did not involve contact with patients, the use of an active intervention or access to medical records as service evaluations rather than research projects per se, and that in these cases NHS REC approval was not required. This verbal advice was confirmed in writing shortly afterwards¹. It seemed that pressure of work falling on RECs as a result of their expanded role in recent years, had now led them to narrow the practical definition of what constituted research to exclude sociological studies as mine. As a study not requiring NHS ethical oversight, the

¹ See Appendix Four.

project was reviewed internally by the College of Human and Health Sciences REC and was granted approval in the first week of January 2010².

Negotiating access

While I was awaiting a definite answer from the Manager of the Wales REC, I began the process of recruiting organisations to serve as research sites. My supervisor assisted me in establishing contacts with individuals involved in the Welsh PPI arena. He approached a contact who introduced us to the Chief Officer (CO) of one CHC. This CHC was identified for purely pragmatic reasons. Further, my second supervisor contacted another actor in the national context who mentioned two other CHCs and introduced my research to them. They both expressed an interest in meeting me to discuss my study. However, one of these two CHCs was too distant from my base in Swansea, therefore, due to funding-related issues, I politely explained to the CO of said CHC that I was unable to include the organisation in my research.

Gaining research access to the sites was a straightforward process. Meetings were arranged with salaried staff from each organisation. My supervisor offered to attend the first meeting with one CHC in order to assist in the negotiations, and proved an invaluable source of expert guidance and moral support in what I perceived as a very delicate context. The CO of the CHC approached through my supervisor's contact arranged for the CO of an adjacent CHC to sit in on our meeting, and both officers supported my involvement enthusiastically and said I could attend virtually all of their meetings. The following day I met the CO and the Primary Care/Patient Involvement Officer of a more distant CHC, and obtained permission to observe their meetings and conduct interviews with similar ease. The only immediate dilemma was whether to observe one or both of the local CHCs to go alongside the distant CHC in a larger urban centre. As I wished to include the larger urban centre as one case study, I decided to select only one of the two CHCs closer to my base.

² See Appendix Four.

In England, the process of negotiation of entry was a little different. The Welsh actor involved in the national context introduced me to a senior figure in a national charity, who agreed to put out some feelers on my behalf, taking account of the fact that for practical reasons (mainly containing travel costs) I preferred sites close to the Welsh border. He suggested three LINKs, however based on the limited time and funding available, I decided to consider the two less distant organisations rather than three in each country. Salaried staff from the two LINKs in my target geographical area agreed to meet me and expressed interest in my study. They approved my involvement with LINKs in principle, but suggested that I attend a management group meeting with both organisations in order to meet volunteers and describe my study, and required me to produce a short written overview of my project to circulate to participants before the meeting. In the event, the meeting went well: informants agreed to my attendance at the organisations' meetings and said that interviews would also be possible.

The process of negotiating access differed somewhat between the two countries. In Wales, I had local sponsors that introduced me to the CHCs and I believe officers did not consult the whole membership, but probably only the Chair or vice-Chair. By contrast, I did not know any local sponsor for the distant LINKs, whose salaried staff required me to consult the volunteers.

Ethnographic work

The next sections provide a description of the methods employed during my fieldwork and outline how the flexibility of ethnographic work allowed me to pursue several lines of inquiry, guided by participants' practical decisions and discussions.

Observations of case studies

As noted previously, symbolic interactionism focuses on the social interactions through which actors create meanings and negotiate the practicalities of their work in a particular social context; Blumer (1969) unequivocally argued that "in order to

treat and analyse social action one has to observe the process by which it is constructed” (p. 56). It was apparent that observing CHCs’ and LINKs’ activities was fundamental to exploring the social processes involved in constructing meanings of PPI. In accordance with Becker (1970), I considered the organisations as case studies. I aimed to produce a detailed analysis of some of their characteristics – namely internal relations, daily work, and the social context in which they operated – but also to identify key processes that might illuminate public participation policies and broader initiatives promoting bottom-up involvement. These aims were consistent with Prus’ (2003) argument that interactionist researchers should undertake comparative analysis of organisations engaged in “doing policy” as a “humanly engaged collective venture” (p.15). Prus (2008) also contended that “things can be known only by comparison with other things – nothing is inherently meaningful in itself” (p.30).

I observed one hundred and nineteen CHC and LINK meetings between January 2010 and April 2011, which covered part of two annual NHS commissioning and planning cycles. Based on examples provided in the literature (Becker, 1961, 1976; Bosk, 1979; Sudnow, 1967; Whyte, 1981), I elected to aim for a fairly long period of fieldwork in order to contextualise the active construction of PPI policy within a broad understanding of local organisations and legal frameworks and how these shaped each other. I believe that the comparative nature of the study required substantial, prolonged involvement in the selected organisations (Becker, 1970) in order to identify patterns of action and understand everyday meaning-making processes. More specifically, prolonged fieldwork allowed me to identify with a certain degree of confidence the sources of actors’ recurrent preoccupations, how they dealt with particular topics, and how they formed and acted upon understandings of their involvement.

I was granted broad entry to the field, which allowed me to observe CHC meetings that were not open to the public (such as the Executive Committee meetings after the reconfiguration). This clearance proved extremely advantageous as it allowed me to observe different decision processes and discussions in which different actors were involved. In addition to regular meetings (full CHC councils and executive committees, LINK working groups, management groups, engagement activities and

training events), I managed to gain access to a few national meetings – namely the All Wales Patient and Public Engagement (PPE) Forum, the National Association of LINks Members (NALM) annual general meeting, and a regional LINks meeting – which provided opportunities to meet other frontline actors involved in the national and regional PPI arenas.

Fieldwork paused for four weeks during the summer of 2010 in order to allow the organisations to adjust to new legislation. In both countries, these legal changes quickly began to shape routinised working practices. LINks faced the task of interpreting the then-new White Paper “Equity and Excellence: Liberating the NHS” (DH, 2010), which outlined how the Coalition Government intended to alter the existing PPI arrangements, and needed to reflect on how those proposed changes would affect current activities as well as the future of the volunteers. Similarly, CHCs had to adjust established working practices to a new organisational structure. Studying LINks and CHCs during periods of change presented an opportunity to shed light on how informants within the organisations drew on their interpretive resources to make sense of top-down changes.

The experience of observing

During fieldwork I was predominantly an observer, although my position significantly changed over time due to increased familiarity and in response to how informants actively constructed my presence within meetings. At the start of my fieldwork I considered myself a total outsider mainly because I had just relocated to Wales and felt that I had to gain familiarity not only with the organisations, but with a sense of Britishness that at the time appeared to constitute an insurmountable obstacle to my social adjustment.

I therefore devised some practical strategies to establish contacts and facilitate initial interactions and conversation with informants. For example, I served hot drinks to volunteers at meetings (as salaried staff did), helped to set up meeting rooms by arranging tables and chairs, distributed papers and closed the doors before meetings commenced. As I felt I could not get involved in many other ways, acting as a helper

seemed an appropriate way to gain familiarity with participants. In addition, I learnt that my total outsider status constituted a reasonable excuse to start a casual conversation without being perceived as nosy or unpleasant. For instance, many informants explained me that they were particularly keen to visit Italy or had previous experience of holidays in my country, or still a few others had Italian grandparents, and as such it was easy for me to engage in discussion concerning these areas of interest.

Salaried staff significantly influenced the form that fieldwork took: they shaped the boundaries of my role and partly contributed to shaping volunteers' perceptions of my presence. For instance, in one CHC my physical position during meetings was subject to constant negotiations; I was allowed to sit at the table only after employed staff ensured that all volunteers had been allocated seats. By contrast, in the other CHC I was assigned a place card like all CHC members. At LINKs' meetings I was encouraged to take a seat next to volunteers, and was never asked to position myself at a distance from the meeting. Some officers always introduced me at the start of a meeting – particularly during the first few months of fieldwork – in order to remind regular participants of my involvement and to inform one-off participants that a researcher was in attendance, although they did not provide much information on the purpose of my involvement. Such support seemed to facilitate and positively influence my interactions with volunteers, whereas the absence of endorsement made me feel like a random participant. I sometimes feared that irregular attendees at LINKs' meetings may have mistaken me for a volunteer. However, in those instances when endorsement was not given, I never attempted to adjust my position by explaining my role and intentions. I felt it would be inappropriate to disrupt the flow of the meeting by providing information on my study at that time, and as such I tended to introduce myself to 'new faces' during coffee breaks and before and after the meeting.

However, it is instructive to note that salaried staff of both organisations endorsed my presence by clarifying the scope of my role in three specific occasions. After my usual introductory statement, they added further information, such as "she is studying the LINK as an organisation, not you, she's here for us and not for you", "she's looking at what we do and not at what you do, okay?" and "she's keeping an eye on

us". This occurred at the LINK Autism Group meeting, the CHC Mental Health Carer's group and at a LINK meeting where a 'new face' was in attendance for the first time. I believe that employees sought to protect participants who were experiencing serious issues and viewed those meetings as opportunities to discuss openly some delicate concerns; in the case of the new participant, the host organisation manager probably assumed that he was not familiar with research practices. By reassuring individuals about the nature of my role, members of staff guaranteed that my presence would not interfere in the development of the meetings; also, I trust that they sought to protect my involvement in contexts that they viewed as particularly sensitive and where they might expect attendees' objections or expressions of discomfort.

In addition to officers' contributions, organisational arrangements of CHCs and LINKs affected negotiations of my role and my relationships with informants (Bruni, 2006). As CHCs had a fixed membership, serving for a maximum of seven years, it was relatively easy to build rapport with informants in such a static structure, and in fact members easily remembered my presence. On the other hand, LINKs had a different organisational structure underpinned by a different conception of participation. LINKs were networks of individuals and community groups in which people could participate as much or as little as they wished, leading involvement to be viewed as a more fluid concept. Both LINKs were made up of working groups and a management group: while the latter had a fixed membership, the former were also attended by occasional and one-off participants and the number of attendees at these meetings generally varied.

Volunteers also influenced on-going negotiations of my role. For example, in two organisations I, like other participants, was usually asked to express my views at the end of a meeting, and on one occasion I was even asked to articulate my preference regarding a specific issue proposed by the management group. However, I always politely refused to extend the involvement beyond my role and contribute actively to the meetings, or to ally myself with the perspectives of particular individuals. I did not wish to become too closely involved with informants even though I also did not wish to be perceived as being too detached from their social worlds or as standing in judgment of their work. Like all novice researchers, I experienced on-going anxieties

with regard to fieldwork. My attempts to negotiate such a precarious position and to strike a sensible balance in developing field relations were tentative (and clumsy) and surely affected by my reserved personality.

Data recording

In the early days of fieldwork I decided against audio taping observed meetings. I was aware that meetings were not recorded by employees, although one officer confessed that she sometimes did – first ensuring that the recorder was hidden behind a set of papers and thus not visible to volunteers. Because recording seemed a sensitive issue, I was concerned that asking to do that might negatively affect the development of fieldwork and relations with informants. In addition, CHC meetings were generally held in fairly large rooms with a sizable number of participants: therefore I believed that any recordings that were made would be of poor quality and that it would be difficult to distinguish between individual voices.

As a result, I chose to rely on hand-written notes. Following Burgess' advice (1984), I took two different types of notes: substantive field notes and methodological field notes. The former comprised a broad description of the venue, which included an account or a sketch of how participants interactively occupied and managed the surrounding space. In addition, I briefly described how people dressed and the mutual interactions that occurred between them prior to the commencement of meetings. The core component of substantive field notes described observed interactions within meetings, particularly in relation to individuals who addressed a particular issue, were especially active in the discussion or tended to be less involved. I also recorded how participants made decisions, primarily in relation to topics that either appeared to be of great interest or were easily dismissed. In taking notes I attempted to comply with Spradley's verbatim principle (1980), which requires the researcher to capture the variety of the language used by informants to discuss and make sense of their social worlds. This enabled me to familiarise myself with context-related language through which participants defined situations and created meanings in interaction, and to identify empirical instances that reflected analytical concepts and theoretical interests. I also engaged in numerous casual

conversations with informants over lunch and coffee breaks, before the start of meetings, or when we happened to travel together to a meeting³. In such circumstances I did not take notes while we were talking, but opted to write down our exchanges as soon as I was on my own (Pope, 2005). Overall, I attempted to portray vividly the events and interactions observed and to avoid abstract language (Spradley, 1980).

To supplement these substantive field notes, I created methodological notes in the form of short commentaries about each meeting I attended and lists of points on which I wanted to follow up during the next visit. Such notes consisted of reflections on my presence during fieldwork and the development of my relations in the field, as well as reports of non-verbal actions – exchanged glances, ironic smiles, eye-rolling – through which informants appeared to express their views.

It may be possible that I was over-cautious in my assumption that a request to record meetings could hinder the development of field relations. However, I felt that the risk of extending negotiations to cover recording outweighed the possible benefits of doing so, especially after the officer I spoke to appeared discomfited when the subject of recording arose. Until the 1960s or even the 1970s, valuable ethnographic studies were constructed on the basis of written notes, and researchers' recording equipment consisted of pen and paper. Following this line of argument, I reasoned that maintaining good relationships with participants was more important than negotiating the use of a digital recorder.

Interviews

I spent a considerable amount of time recruiting and interviewing informants in order to supplement my observational data through the exploration of individual meanings and perspectives. I considered these interviews as socially constructed joint collaborations between myself and participants, and I was aware of Dingwall's (1997) argument about the nature of the information created in interaction:

³ I sometimes met informants on local buses as we were heading to the meetings' venues; additionally, some of them offered to give me lifts to reach the designated venues or to get to the train station after the meetings ended.

The data produced by interviews are social constructs, created by the self-presentation of the respondent and whatever interactional cues have been given off by the interviewer about the acceptability or otherwise of the accounts being presented. (p.59)

In support of the combined use of interviews and observations, Khan and Jerolmack's (2013) reflections on a study exploring how meritocracy was reproduced in everyday encounters in an elite boarding school illustrate the fundamental role of interviews in uncovering how students' discourses sustained an idea of meritocracy that evidently contrasted with practices of 'doing privilege'. Khan and Jerolmack (2013) encouraged researchers to consider informants' accounts in combination with observations and the broader social context in which action is shaped. I thus adopted a middle-range theoretical position by being wary regarding the accuracy of interviewees' accounts and taking account of the situated nature of verbal meanings produced in formal encounters. Although participants expressed various perspectives on a variety of topics, I found evidence of shared perspectives on many issues. Certain recurrent themes and concerns and areas of mutually-agreed understanding emerged from my data. This was true of the interview accounts, but also carried across into observed actions, when, for example, I investigated how far interview accounts of roles matched how roles were enacted in practice, and how participants aligned action with institutional and organisational constraints.

In total I conducted seventy-one semi-structured interviews, three of which were undertaken in two sessions each because those informants had appointments with family members; I also conducted three interviews with actors from the Board of CHCs. I interviewed three CHC officers twice as a result of the changes to their roles after legislation, and I interviewed the host organisation manager twice to gain some reflections on the context of organisational transformation. I also arranged an additional interview with a volunteer to further pursue several issues related to the "Equity and Excellence: Liberating the NHS" White Paper (DH, 2010)⁴. Additionally, two participants agreed to assist me with my study but decided to provide written responses to questions that I emailed to them beforehand rather than being interviewed in person.

⁴ These repeated interviews were formally arranged and tape-recorded.

All interviews were recorded after having obtained permission from participants. Although their length varied significantly – between eighteen minutes and two hours – most participants were interviewed for as long as needed. In a few interviews with professionals I had a limited amount of time (usually about an hour) but felt that this restriction did not reduce the quality of the data obtained.

I used an interview guide covering broad topics, which evolved over the course of my fieldwork as I gained familiarity with informants, and identified some observed discussions or actions for further investigation in individual interviews. I adopted a semi-structured format while retaining ample margins of flexibility to adapt to participants' styles of narration and preferences regarding the issues discussed.

The streamlined version of the interview guide covered the following topics: actors' backgrounds and their motivations for joining the organisations; organisational roles and relations with various stakeholders (such the NHS, LAs, and the voluntary sector); conceptions of PPI and practical examples of policy. After the CHCs' reorganisation, I made additional inquiries about the transition; similarly, I was interested in exploring LINK participants' preliminary reflections on the new White Paper (DH, 2010) and how the proposed changes to PPI arrangements affected their everyday work.

I began conducting interviews after a few months of observations. Participants were informed when I negotiated entry to the field that interviews would take place, but I wanted to familiarise myself with them, attain an understanding of working practices and observe some discussions or decision-making processes before undertaking any interviews. During the selection process, I was not concerned with ensuring that interviewees came from different age groups, sexes/genders or ethnicities, as investigating relationships between participation and socio-economic characteristics was beyond the scope of the study. Rather, I sought to select volunteers with different characteristics, for example, both employed staff and individuals who had various degrees of contact with the organisations. I was also interested in interviewing professionals who regularly attended the organisations' meetings. In England, I engaged in numerous informal talks with people whom I met by chance at

LINK meetings and one-off events, such as training sessions and informative meetings.

My observations certainly informed the selection of my interviewees. I sought to diversify the recruitment of informants in relation to their observed influence within meetings, their viewpoints or their levels of contribution. Some insiders, especially employees, pointed other people for inclusion in my study, and I accepted and followed up on these suggestions. A few people approached me directly and volunteered enthusiastically for interviews or reported – albeit with less obvious enthusiasm – that they were available to assist me. I tended to arrange interviews in places which were familiar to participants. The CO of Rainbow CHC and the host organisation manager kindly allowed me to conduct interviews in the meeting rooms at the organisations' offices whenever they were available. I arranged to meet informants from Blue CHC in a variety of settings, including participants' homes, the local university, public cafés and LA offices.

Throughout my study I tried as best I could to practice the “craft” of fieldwork – the careful cross checking and planning - outlined by Becker and others and mentioned earlier in the chapter. I stayed in the field as long as was realistic within the confines of a doctoral study, I collected a very large corpus of data, I attempted to corroborate findings by using multiple sources (and sometimes more than one method), and I directed ongoing observations and interviews over time to fill in gaps in my data of which I was aware. Generally, I was not reliant on interview accounts alone to establish propositions about which I had no observational data, and indeed was often in the position to use accounts volunteered to other participants as opposed to accounts offered directly to me as a researcher. As explained above, the interviews were started well after observations had begun, and were generally used to delve deeper into issues already identified as important from observations. When combined with use of background documents, this meant that I often has several sources of information about any given issue.

Managing interview data

At the beginning of my doctoral studies I chose to transcribe all interviews in full. I reasoned that this could be useful in developing familiarity with the data prior to undertaking the analysis and also in writing up the thesis. Listening to and transcribing participants' accounts also guided me in selecting topics to investigate further in the observations and interviews that followed.

Conducting observations and interviews at four different sites proved to be quite stressful and time-consuming. As such, I had to make certain practical decisions about data management: I ensured that I cleaned up my notes as soon as possible after each meeting, usually within twenty-four hours, and that I also transcribed interviews as soon as possible. However, I was not always able to put this into practice; in a few cases, I only managed to transcribe interviews weeks after they took place. Nevertheless, notes concerning the physical environment in which I met with participants and my general impression of our interactions, along with points of particular interest, were written up shortly after interviews.

Documents

Conscious of the advantages of including documentary analysis within a research study (Shaw, Elston, & Abbott, 2004), I included LINKs and CHC documents acquired during fieldwork. However, Murphy and Dingwall (2004) pointed out that documents "must be seen as artfully constructed" (p.4), or as assemblages of ad-hoc images that organisations may create in order to shape overall impression management. Documents may omit participants' discussions, negotiations or minor deliberations which may nevertheless provide insightful information on the people studied; as such, these omissions may affect external perceptions of organisations' identities. Accordingly, documentary analysis does not merely view documents as topics, but rather highlights the importance of the researcher's active interpretation of how documents "function in specific circumstances" (Prior, 2004, p.91).

I obtained sets of papers related to meetings and one-off events from members of staff. These consisted mainly of engagement reports, events flyers, publicity leaflets,

working plans, NHS and LA documents, policy documents, and guidelines; I generally received papers from CHCs via post several days prior to meetings. I also downloaded data from CHCs' and LINKs' websites in order to investigate what information was available online and how this was disseminated in the public domain. This collection of documents assisted in illustrating the social and policy background of the engagement bodies.

Ethical considerations

The study did not pose unusual ethical challenges. I aimed to comply with the Statement of Ethical Practice for the British Sociological Association (BSA, 2002) to guarantee ethical conduct during fieldwork. I reassured informants that participants' names and all research settings would remain anonymous by assigning pseudonyms to everyone mentioned in the thesis; this was an easy task since both volunteers and employed staff were ordinary members of local communities. I did not face particular issues in concealing the identities of NHS and LA professionals since they worked for very large organisations, although in Wales the number of LHBs is limited in comparison to the number of PCTs in England. Also, I did not reference the population data as reported in the second part of this chapter in order to preserve anonymity.

I attempted to be as open as possible over the course of my fieldwork (Murphy and Dingwall, 2007). Before interviews I was available to provide any additional clarification regarding my study as desired by participants, and I provided participants with information about the study and myself when we engaged in conversation during the interview process. Despite my best efforts, there were a few situations where the issue of informed consent and the responsibilities of the researcher and employed staff were raised, and where I experienced discomfort. For instance, on one occasion I was attending a public meeting regarding the future reorganisation of the NHS in England, where some invited speakers from the local PCT discussed the proposed changes and how they were going to affect local services. Volunteers from both LINKs were in attendance as well as some employees and several ordinary members of the public. The latter were not informed about my

presence: it was a public meeting and I judged that my presence would not pose particular issues. Employees and volunteers did not raise any concern. However, one participant, who attended some of the LINK's meetings in the past, expressed concerns about the presence of a researcher in the final session of the event and she doubted that people in attendance were informed about the study that said individual was undertaking. I thus raised my hand in order to allow people to see me and the facilitator of the event asked me to go on the stage and provide some information about myself and my research. I remember being upset: I only managed to provide a quite confused statement about my Ph.D. The facilitator invited the people in the audience to contact me personally for further clarifications. A participant, whom I met before at another event, approached me and stated "I haven't got anything against you but your supervisor has to know that what you're doing isn't quite right" and I gave her my supervisor's email address. I started crying, and LINKs members of staff invited me to go to their offices where they sought to reassure me that I did not do anything wrong; some volunteers also expressed concerns about my emotional state. In addition, I rang my supervisor to inform him about the episode. The person contacted my supervisor eventually, who replied and clarified my position and the context of my study, and the exchange ended soon afterwards. This episode clearly shows that although it is widely assumed that researchers are allowed to attend public meetings without obtaining informed consent from all participants, some people may still want to be aware of researchers in attendance and the nature of their study.

I planned to attend another public meeting in the following month, and so raised my concerns with members of staff in order to prevent a similar episode from occurring. The LINK Chair suggested that it might be best to inform all attendees about my presence at the event by emailing them a simple overview of my study; in addition, they were invited to express their concerns if they had any. Nobody objected.

I also faced a dilemma about the selection of the venues in which to interview NHS professionals. From my contact with the Wales Ethics Committee about ethics and access, I was aware that I could not conduct interviews on the premises of an NHS body without separate access approval, which involved an application for risk assessment. This was a complex process with several NHS Trusts and their respective risk assessment committees potentially involved, and I was worried that

such applications could significantly delay my fieldwork. I therefore explained my concerns to professionals and asked them whether they were willing to be flexible so that I could find a way of doing the interview without breaking the rules. The professionals approached agreed to be interviewed and to meet me on alternative premises away from the NHS sites.

There were no potential participants under the age of 16, and as such no one was excluded on the grounds of age.

Lastly, I trusted that the few informants with cerebral palsy were fully able to understand that I was a researcher and that they were assisting me by explaining their viewpoints in interviews.

Data analysis

In the early days of my doctoral research, by reading several articles from the journal *Symbolic Interaction*, I realised that symbolic interactionist studies provided general accounts of the method of analysis, rather than reporting the use of an exhaustive procedure to make sense of data.

I felt that removing building blocks from interactive contexts and positioning them within a fixed-meaning codified scheme could limit the breadth of a reading of my data. A cornerstone of symbolic interactionism is the idea that meanings are emergent and subject to constant interpretation in relation to the broad context that it also helps shape. Murphy and Dingwall (2003) claimed that “the important point is that *all* interview talk, like all other naturally occurring talk, is *always* socially and contextually constrained. What we say and how we say it is never divorced from the context in which we say it” (p.85). Further, Wellman (1988) strongly advised researchers to understand the overall ‘scene’ within which actors develop their viewpoints.

As a result, despite the considerable amount of data generated I decided against using qualitative software such as Nvivo to reduce my data because I reasoned that the use of qualitative software might constrain the scope of analysis rather than facilitating

the process. I would also have had to invest a considerable amount of time in learning how to use the software, and preferred to spend such time gaining deep familiarity with the data set. I therefore decided to print off all of the interview transcripts and field notes and analyse them manually, using coloured highlighters and notes to identify common concerns and themes reported by informants and to identify the relationships between ideas. In particular, I decided to draw broadly on Braun and Clarke (2008) description of thematic analysis in order to identify recurrent themes and patterns of action across the data that were relevant to the research questions. I felt that the flexibility of this approach could be adequately combined with the theoretical framework of symbolic interactionist (Braun and Clarke, 2008) and its emphasis upon the exploration of meanings in informants' everyday interactions as they carried out the work.

In practice, I read several times individual transcripts of interviews and notes of observed meetings in order to familiarise myself with them and ensure that I could identify quotes and key words that seemed relevant to the overall aims of the study. Some ideas did relate to each other and overlapped; sometimes participants expressed consistent views about a certain aspect across the four sites (such as understandings of the volunteer's role), whereas at times I noticed key differences in how informants thought and talked about other parts of their everyday experiences within the English and the Welsh bodies (such as the volunteers' understandings of the expected organisational position of members of staff). I also attempted to identify the processes that appeared to shape significantly understandings and the implementation of PPI, which I grouped in broad areas, such as roles, relationships and institutional frameworks. For instance, at a certain point I felt strongly that negative images of 'the public' were used particularly by volunteers to construct self-understandings of roles (and the tasks to be accomplished within the organisations). This sketch, however, was supported differently by officers in LINKs and CHCs in the context of different institutional frameworks as communicated in guidance. In addition, by drawing on such images of 'the public', informants appeared to question the actual added value of involvement initiatives against a social background of apathy. Once I completed this process for all the participants and the fieldnotes I sought to make sense of all these ideas and themes in light of all the data together.

In order to being able to continue ensuring a careful approach to the corpus of data, the two supervisors also read some transcripts and we discussed how they could be interpreted and how they could illuminate further subsequent analysis. In addition, I also presented some of the findings at departmental research group events and at various conferences. Furthermore, I was invited at a meeting to disseminate my preliminary findings to involved stakeholders; in particular, my presentation focused on conceptions of PPI and the implications of undefined roles in everyday interactions within local arenas.

As Charmaz (2004) suggested, the writing process is crucial to engaging with data and shapes the development of connections between instances and ideas. I certainly underestimated the impact of writing in qualitative studies in the early days of my research; in particular, I failed to realise that the accurate selection of 'right' words was essential to constructing a coherent and sound narrative. My supervisor constantly encouraged me to refine ideas and analyses by highlighting the need for precision in the use of terms; during my writing-up, he also pointed out the contradictions emerging from my ethnographic representation, and suggested 'mull[ing] it over' in order to eliminate weakness and circularity from my arguments. My supervisor's guidance was essential in showing me the pragmatic significance of writing in a manner that I interpret as consistent with Emerson, Fretz and Shaw (2001) view that "the writing ethnographer has to make writing choices in real time" (p.365).

Overall, I share Oakley's (2002) view of analysis as a uniquely human interpretation of the fieldwork experience:

Interpretations are attained [...] through the memory of field experience, unwritten yet inscribed in the fieldworker's being. The ethnographer, as former participant observer, judges the authenticity of his or her conclusions and interpretations in terms of the total experience. (p.30)

Conclusion

This chapter delineated my symbolic interactionist approach to methodology by illuminating how I have applied it in practice throughout the development of the study. Further, I outlined the fieldwork process and argued that a traditional interactionist approach is well suited to examine front-line actors' practical construction of PPI policies in the course of their work. I also discussed some ethical considerations, the process of data analysis and the limitations of the study. Having established the importance of the different dimensions of context in symbolic interactionism, the next chapter outlines the social and organisational context of the selected study sites.

CHAPTER FOUR

DESCRIPTION OF RESEARCH SETTINGS

Introduction

The chapter provides a description of the research settings by mapping out the social and organisational contexts of the selected CHCs and LINKs. A brief sketch of the key organisational groupings – salaried staff and volunteers – is also provided although these will be outlined in greater detail in later chapters.

The sites comprise a combination of urban characteristics (two major cities and a medium-sized city) and typical features of rural areas (a mix of small towns and villages across their respective countries). The descriptions presented are mainly based on extracts from my field notes and interviews: they serve the purpose of contextualising the organisations studied within the geographical locations and physical environments in which they performed the role of citizen-engagement groups.

As explained in Chapter One, Wales and England pursued divergent policies in relation to PPI arrangements during the course of my fieldwork. The Coalition Government in Wales introduced proposals to restructure CHCs in 2009 following the reorganisation of LHBs, and new bodies were formed from 1st April 2010. In Westminster, the national Coalition Government proposed significant reforms of the NHS in England, which included the abolition of PCTs and their replacement by Clinical Commissioning Groups (CCGs), and the evolution of LINKs into LHW. The latter were to be presided over by HealthWatch England, a Care Quality Commission's (CQC) arm's-length national body. I was concerned that these organisational changes could affect my access to the research sites. However, my study was not an evaluation and did not seek to compare situations before and after reform and I realised that structural reorganisation and proposed changes could enrich understandings of participants' social worlds rather than spoiling my research design. In fact such changes provided a valuable opportunity to gain a wide variety

of insights into how informants would make sense of the policy documents and the political input they received.

CHCs

When I started my fieldwork, I was studying Blue CHC and Rainbow CHC. However, as a result of the 2010 reconfiguration, they merged with neighbouring CHCs to form Blue Sand Hill CHC and Rainbow and Rural County CHC. The new organisations were coterminous with the new LHB, whereas previous CHCs were turned into Local Committees (LCs), which became coterminous with Local Authorities (LAs). Consequently, from that point onward I decided to focus my fieldwork on Blue LC and Rainbow LC, although I continued to observe full council CHC meetings in order not to lose sight of the organisational context as a whole.

Also, the Community Health Councils (Constitution, Membership and Procedures) (Wales) Regulations 2010/288 (W.37) introduced an Executive Committee (EC) “to oversee the conduct and performance of all relevant local committees and to ensure the effective delivery of the Council’s statutory duties and core functions” (p.19). The EC was formed by the Chair and vice-Chair of the CHC, the Chair and vice-Chair of each LC, and the CO.

Rainbow City

According to the Office for National Statistics (ONS) mid-year estimates for 2010, the City of Rainbow has a population of approximately 341,000 and as such is one of the major cities in Wales. An article published on a travel magazine described the city as follows:

It's a spacious, charming and interesting city with an optimistic buzz. It's a green city by any stretch of the imagination meaning a visit here won't cost the Earth. There is more green space per person than any other UK 'core city' with a vast green swathe stretching right into the heart of Rainbow [...] On top of all of this, Rainbow has been designated the world's first Fair Trade Capital, encouraging

ethical trading and fair prices for producers in Third World countries. This eco theme also winds its way into the fabric of what Rainbow does best — shop. It's a buyer's, moocher's, and vintage hunter's paradise with quirky boutiques.

With regards to health service provision, Rainbow City is served by Rainbow and Rural County LHB, which comprises nine hospitals, seventeen health centres, and sixty-eight general practices with twenty-five branch surgeries. It is also one of the primary teaching health boards across Wales, and is closely connected with Rainbow University.

Workplace

Rainbow CHC office was situated in a three-floor office building in the city centre of Rainbow, next to the main shopping area and to several bus stops, and within walking distance from the train/bus station. There was no sign outside the building indicating the presence of the CHC. There was a reception desk with a porter in attendance from 8am to 5pm; from the front door one walked down a short corridor and found the CHC office on the right side. A notice signalling the presence of the CHC was on the door and, as it was never locked during office hours, visitors could easily access the office. The office itself was laid out in a square open-space floor plan and had a cosy atmosphere. Two big windows looked out onto a busy street, the civic centre and a park, and each employee was provided with a desk. A large photocopier was situated in the entrance to the office, as well as a sizable display of various leaflets about the CHC, NHS services and local voluntary organisations. At the left end of the office was a private office for the CO, while the right end of the office held a meeting room and, next to that, a small but well-appointed kitchen.

The office environment changed significantly in October 2010, when the then Deputy CO (who had held the post of Primary Care/Patient Involvement Officer when I started fieldwork) was appointed CO and the three people forming the advocacy service temporarily relocated to another office on the other side of the city. The reconfiguration also included the creation of a Patient and Public Engagement Officer role, which was filled by the Office Manager of Rural County CHC (with

which Rainbow CHC had merged). A new secretarial assistant joined the CHC team before Christmas time that same year as well.

The office layout was altered to accommodate the expanded CHC team; these alterations reduced the space allotted to each employee. The main entrance became an informal waiting room for people visiting the office and was narrowed by the placement of a long tall bookcase along its left side. An impromptu wall for the CO's office was created by placing some plastic panels against one side of the bookcase and around a desk, two chairs, a cupboard and a clothes hanger. This space was not ideal for private conversations – one could determine whether the CO and his interlocutor were discussing delicate issues by their tones of voice. When the advocates moved back into the Rainbow City office, they were placed in the former CO's office in order to have a private space to safeguard issues of confidentiality with potential complainants.

Both volunteers and employed staff viewed the central location of the office as a key aspect of the organisation: some members 'just popped in' when they happened to be in the city centre, and officers reported being pleased to be visited. This contributed to establishing strong bonds within the organisations, and will be examined further in Chapter Six's discussion of the negotiations of relationships within CHCs.

Staff structure

When I started my fieldwork, the then CO had been in post since 1996. He retired in April 2010 when a new CO was appointed. In September the then Blue Sand Hill CO became ill and the new Rainbow and Rural County CHC CO was asked, presumably by the Director of the Board of CHCs, to support the management and the work of Blue Sand Hill CHC for the time being. However, by the time the Blue Sand Hill CO's health improved and he was able to return to work, the Rainbow and Rural County CO had been appointed the new CO and appeared to have officially taken his place. As a result, the Deputy CO of Rainbow and Rural County acted as interim CO for approximately one month until being appointed CO after a successful interview in October 2010. In May 2011, when my fieldwork ended, the CHC staff consisted of

a CO, a Deputy CO, a Primary Care/Patient and Public Engagement Officer, two advocates and an advocacy support officer, an administrative assistant to advocacy service and Patient and Public Engagement functions, and a Personal Assistant (PA) for the CO.

Staff members generally wore business attire; the CO and the Deputy always wore a suit while female staff members tended to wear casual business clothes.

Members

The new merged CHC should officially have had twenty-four members, of which six were to be appointed by LAs, six by voluntary organisations and the remaining twelve by the Welsh Government. However, only two of the members of the former Rainbow CHC reapplied for the new CHC. Although both were successfully appointed by the Welsh Government, one decided to leave the CHC due to strong reservations regarding the new organisational structure. Additionally, four former members continued volunteering in the new body as co-opted members, with their affiliation subject to re-confirmation after July 2011, one year from the date of their appointment.

Blue City

According to the ONS mid-year estimates for 2010, the population in Blue City was approximately 237,300 at the time of my fieldwork. Blue City was one of the more active urban centres at the time of the Industrial Revolution and experienced an influx of immigration from both within and outside Wales, and as such rapidly grew and expanded. After the post-World War II decline of heavy industry, Blue City mainly focused on the service sectors which are at present the main source of employment for the local population.

With regard to the provision of health services, Blue City is served by Blue Sand Hill LHB which, like Rainbow and Rural County LHB, is also a teaching hospital. The

whole area comprises four acute hospitals, several smaller community hospitals and seventy-seven general practices.

Workplace

Blue CHC's office was situated in Trees Area, a peripheral zone of Blue City. Its specific location was on top of a fairly steep hill off the main road, within walking distance of the only bus stop in the area. Buses ran on an hourly basis and stopped at about 4pm. I myself did not have access to a car and therefore had to rely on public transport to get to this area; as a result, I usually arrived forty-five minutes before the start of each meeting, since the only alternative option would have been to arrive fifteen minutes late.

The main car park was inaccessible although some individual accessible spaces were available in the back side of the building. As Mel, a volunteer, reported, "a lot of people don't know where it [the office] is and as you find it's not very accessible". The office itself was located in a two-storey building: one had to ring a bell to gain entry to the building through a non-automatic door, and then one had to ring another bell on a glass door to gain entry to the CHC office. Inside, there was a tiny waiting area with two armchairs and a small table displaying several leaflets on health-related issues. The advocates' room was next to one of the armchairs, although there was no sign outside it. The rest of the offices were laid out along a narrow corridor. On the left, there was a small room with photocopiers and many reams of copy paper, and after that a meeting room where some CHC meetings were usually held. Here there was also a small table with a hot drinks machine. On the right side of the corridor there were three other rooms. When I started my fieldwork, one of these rooms was the COs office while another was the PA's office. The remaining room was the Sand CHC CO's office, as this office space was shared by Sand CHC at the time. However, as in Rainbow CHC, the physical office environment was modified after the reconfiguration. The COs of Sand CHC and Blue CHC retired soon after the changes were implemented, and the then new PPE officer and the two secretarial support assistants shared a common room. The Deputy CO had his own office, and the meeting room was transformed into a new office for the advocates and advocate

assistant. One consequence of these changes was that the advocates and other officers did not have a quiet space for private conversations – whether with CHC members, potential complainants or members of the public.

The LCs' offices merged after the reconfiguration in order to consolidate all CHC staff in a single workplace. Although Blue CHC and Sand CHC already shared the same offices, Hill CHC's office was located twenty miles away in the centre of Hill town. This office was also not accessible and had no accessible car park on site, although the train station was within short walking distance. The then Hill CHC CO initially remained in his office after becoming the new Blue Sand Hill CHC CO. When he was replaced due to health-related issues, the new CO moved into the Trees Area office, where all employed officers remained until relocating to a new office in the centre of Sand town in May 2011.

Staff structure

I negotiated physical access to the organisation with the then Blue CHC CO, who retired in May 2010. The then Hill CHC CO was appointed as the new Blue Sand Hill CO when the latter became ill, as outlined previously. The former Blue CHC PA was assigned the new role of PPE Officer, and in April 2011 a new advocate and two administrative assistants joined the advocacy team.

Members

According to the new regulations, Blue Sand Hill CHC should have had thirty-six members, of which nine were to be appointed by the LAs, nine by voluntary organisations and the remaining eighteen by the Welsh Government. Four former Blue CHC volunteers re-applied for membership and were successfully reappointed as full members in the new Blue Sand Hill CHC.

LINKs

The selected LINKs, Red and Greenshire, were supported by the same host organisation – Sunflower – a large voluntary organisation based in Aquarium, an area on the border between Red LA and Greenshire LA. Sunflower’s primary aims were to promote local collaboration and participation and to improve health and social care services in the area. Most of the salaried staff of both LINKs shared the same offices, and two other officers were placed in an adjacent room. This section provides an overview of the geographical characteristics of the two selected English regions, followed by a description of the organisations’ workplaces and staff structures.

Red LINK

Red City is considered one of England’s eight ‘Core Cities’: the most economically developed urban areas outside London. According to the ONS mid-year estimates for 2010, the population of Red LA was approximately 441,300.

With regards to health care service provision, Red Area was served by several NHS organisations. Red NHS Foundation Trust comprised eight hospitals in the city centre and peripheral areas. North Red NHS Trust, a large teaching hospital, provided health care services to Red Area, Greenshire and two other adjacent Local Authorities. It comprised two large hospitals and several smaller centres, as well as a new hospital that at the time was still being developed. Additionally, Red Community Health was a social enterprise commissioned by the NHS to provide community-based health care services.

Greenshire LINK

According to the ONS mid-year estimates for 2010, the population in Greenshire LA was approximately 264,800 at the time of fieldwork. Greenshire is a large rural area with several small towns and villages, some medium-sized towns with a total

population of approximately 32,000, and no major cities. The main source of employment for the area was the service sector, mainly the LA.

Health care services were provided mainly by Greenshore NHS, a Primary Care Trust which commissioned the services of North Red NHS Trust, and University Hospital Red NHS Foundation Trust. Mental health services were provided by a neighbouring mental health NHS Trust.

Workplace

Sunflower's offices were located within the Butterfly Centre, which was locally established as a large conference centre in a residential neighbourhood of Aquarium, one of the major charity sites of Red City. The Butterfly Centre was surrounded by well-kept detached and semi-detached houses, a small shopping centre with various shops and restaurants, and a few bus stops. Red City Centre was about thirty minutes away by bus, and there were also direct transport links with one of the city's major stations, the university campus and some local hospital sites.

Butterfly Centre was fully accessible, with several disabled car spaces located by the automatic main entrance door. The reception area was located on the right side of the main entrance lounge. A volunteer would welcome visitors, ask them to sign the register and answer enquiries if needed; during many visits, I noticed that some of the volunteers assisting visitors were (severely) disabled. By the reception desk a large notice board displayed information about daily meetings and events. Two corridors started on both sides of the board. To get to the Sunflower offices, one walked down the corridor on the left, went through an automatic door, and rang the bell on the first glass door on the left; the Sunflower offices were laid out along another long corridor with several rooms located on both sides. The host organisation's main office was the second room on the left, and was quite small despite accommodating four members of staff from both LINKs. Due to the physical layout of the office, it was difficult to sustain a private conversation with any of them unless the conversation could be moved to the adjacent meeting room. When I started my study, a research officer and a publicity and communication officer were

also working for Red LINK, and shared the office with a few employees of other services provided by Sunflower.

Red LINK experienced some employment changes during the course of my fieldwork. The development worker left in October 2010 and was replaced soon afterwards, while an additional development worker was employed on a temporary basis to raise awareness of LINKs within local communities and establish new partnerships with a wide variety of local actors. The research officer and the publicity and communication officer were made redundant in March 2011.

Participation appeared to be more fluid within LINKs than within CHCs. As I shall return to in greater depth in the empirical chapters of this thesis, LINKs were established as networks of individuals and community groups, and in principle volunteers were not appointed and were not subject to specific time commitments.

Conclusion

The chapter described the social and organisational contexts of the research sites. The next five empirical chapters will outline the stories of the stakeholders involved while they constructed PPI in the course of the work as I made sense of them.

CHAPTER FIVE

CONSTRUCTING ROLES AND RELATIONSHIPS WITHIN LINKs

I mean the way LINK was started you know...It was sort of 'We are the LINK!'...Who's the LINK? You know, you look at the person next to you, we've all got different ideas, different experiences, different reasons to be sitting here¹.

Introduction

The present chapter, in combination with Chapters Six through Nine, explores the processes of construction of the meanings of PPI within two Welsh CHCs and two English LINKs. Before presenting my findings, I will provide an overview of the key arguments developed in the empirical chapters by drawing on interviews, observational data and documents that I acquired during my fieldwork. In Chapters Five and Six I examine how actors made sense of their roles and built relationships in local arenas. Although policy was broadly constructed from above, actors had a relatively large scope to interpret it and to make practical decisions about its planning and implementation. Such negotiations occurred within the two differing national statutory frameworks that set expectations of how actors were to improvise roles and build relationships. In Chapter Seven I discuss how informants (with some exceptions in LINKs) generally constructed 'the public' against established understandings of roles and how the positive attributes underpinning volunteers' abilities to contribute meaningfully to their organisations led to a perception that members of the general public lacked the necessary skills and knowledge to look at "wider issues" of public interest. I also show how this tension seemed to create a 'belongingness divide' between LINKs/CHCs and the ordinary people who constituted 'the public' they served. In Chapter Eight I discuss how CHCs and LINKs related to the domain of PPI. This analysis includes examining how policy documents constructed the role of the organisations in relation to said policies and

¹ Quotation from the interview with Sheila, a volunteer from Red LINK.

how officers and volunteers negotiated the meanings and the implementation of training provisions. Further, I describe the roles of the PPE officers in Wales and the development workers in England as emerged from guidance and regulations. I then examine how volunteers, officers and professionals built on the key findings of the previous chapters to negotiate conceptions of PPI. Lastly, in Chapter Nine I present how the organisations 'did PPI' locally by discussing the interrelatedness of officers' and volunteers' negotiations of roles, and how the organisations and NHS professionals interacted in relation to PPI. I also provide a brief overview on PPI in social care, and then I draw on the concept of juridification to illuminate actors' interpretive processes and how top-down frameworks intersected with bottom-up spaces in constructing the meanings of PPI.

The rationale for the choice of PPI as the topic of my doctoral studies, as explained in Chapter One, frames my decision to dedicate two chapters to constructions of roles and relationships within LINKs and CHCs. At present, PPI is a confused and contested concept for which we have various theoretical models and definitions (Gibson, Britten, & Lynch, 2012; Staniszewska, Herron-Marx, & Mockford, 2008; Tritter & McCallum, 2006; Tritter, 2009). In the British context in particular, where administrative devolution has resulted in divergent NHS policies, we need studies that show whether headline policies differences are reflected in differences in PPI policies in practice. Actors involved in advancing the work of the organisations and negotiating strategies to implement PPI activities did not act in a regulatory void: rather, they operated within differing institutional frameworks setting out different rules about who could participate and how. For instance, the numerous guidelines issued by the DH and the NHS Centre for Involvement (2006, 2007, 2008) provided a relatively loose definition of the role of the host organisations within LINKs: namely, to support, enable and facilitate the activities of the organisations. Further, the document "Help build a better and social care service. Local Involvement Networks (LINKs) explained" (DH, 2008) stated that "the more people that get involved in your LINK, the stronger and more influential it becomes" (p.2) and it strongly emphasised the message that "each and everyone's views will be taken seriously by your LINK" (p.5). As I will explain in Chapter Six, members of CHCs,

in contrast, were selected by formal appointment, which in principle comprised all the stages of a job application process.

These expectations about LINKs recognise that volunteers will be drawn from diverse social groups and have differing needs and experiences. Such diversity may have also influenced volunteers' interactions with salaried staff in their facilitative roles. Diversity may result in different expectations of actors and in how they construed their roles and relationships. This may be important as PPI is a domain where there are wide margins for negotiation, and actors' conceptions of PPI are heavily influenced by understandings of roles and relationships, as we shall see in Chapters Eight and Nine.

In addition, social roles and multiple forms of relationships constitute key building blocks in symbolic interactionism, and are variously explored in several sociological studies informed by such a perspective (Anderson & Bondi, 1998; Charmaz, 1983; Eayrs, 1993; Kato, 2011; Loe & Cuttino, 2008; Milligan, 1998; Smith & Bugni, 2006; Strauss, Schatzman, Bucher, Ehrlich, & Sabshin, 1964). Through interactions individuals form their conceptions of roles related to the context in which they are acting by considering official and informal rules framing actors' courses of action. Consequently, symbolic interaction is a promising approach for advancing empirical understandings of the social nature of roles and of how they shape organisational meanings, relationships and working practices.

Although the present chapter is primarily about the English context and actors' struggles to adjust roles and maintain relationships, I will also introduce some preliminary comparisons between LINKs and CHCs to highlight similarities and contrasts against a backdrop of differing rules and expectations in the two countries. Firstly, I will present volunteers' motivations for becoming involved in LINKs, and will also look at staff members' backgrounds. This raw material is relevant to understanding how they made sense of their roles through interactions and based on their life trajectories. Secondly, I will provide a sketch of the framework of policy and guidance that regulated the functioning of LINKs in England, and will show how officers and volunteers interpreted their roles and negotiated working relations against the background of this regulatory context. I will pay particular attention to

some of the main issues that actors faced in constructing relationships, and will also explore how NHS and LA professionals contributed to creating the model of an ideal volunteer, whose key features soon turned into implicit expectations regulating symbolic acceptance within the organisations. I will also examine informants' preliminary understandings of the coalition government's proposal to introduce LHW as the new formal arrangement for PPI. Lastly, I will reflect on New Labour's rationale for the selection of the network as the organisational structure to embody PPI locally and will illustrate how volunteers interpreted it in everyday practice.

Volunteers' motivation for involvement

Volunteers' motivations for becoming involved in LINKs were often related to first-hand experiences of health services, in many cases concerned with what had happened to family and friends. The majority of participants were retired, with a large amount of free time that they wished to dedicate to voluntary activities. A combination of experiences, interest for the health services and a desire to invest their spare time meaningfully thus motivated them to volunteer. For several other participants, involvement in LINKs represented a continuation of their participation in the older PPI Forums, and even CHCs. In a few cases, professionals approached volunteers or other individuals already involved in the local PPI arena, and were encouraged to join the organisations on the basis of their knowledge, skills and their potential ability to contribute significantly to the LINK. These individuals had extensive experience within the voluntary sector, and high professional status: my observations also suggested that they were very articulate and confident in voicing their views. I observed a similar scenario in Welsh CHCs in relation to the motivations and informal recruitment of volunteers. For instance, one CHC adopted an informal pre-selection process for volunteers, where certain candidates were informed about vacancies and encouraged to apply. I will expand upon this aspect in Chapter Six.

Additionally, a few volunteers viewed their specific professional background and technical skills - albeit not necessarily health-related - as something that would add value to the LINK. The following extract from an interview with Ken, an active

volunteer of Greenshire LINK with expertise in project management and engineering, exemplifies this:

I mean I've been a project manager; I try to think in all dimensions, you know, not just the thing that has to be achieved: how much it's going to cost, how long it's going to take, how easy is it going to be to implement. Other people just think 'Oh that would be a good idea', they don't worry about the difficulty, the cost, the time and all that.

A few other CHC members expressed similar views, suggesting that the health system could benefit from their professional knowledge. For instance, Ryan, a volunteer in Blue Sand Hill CHC, stated that his set of engineering skills in the quality improvement system could be applied to improving the processes in the NHS.

Andy, a dedicated volunteer in Red LINK, also viewed his background in microbiology and past work experience in a hospital as his main qualifications for his involvement in LINK. From my observation of meetings as well as from his interview, it was evident that his volunteering was strongly influenced by his peculiar interest in hospital infections, a topic which found its way onto a working group agenda due to his attempts to prioritise it. Similarly, CHC members Janice and Pauline, transferred their interests from the professional fields they were involved in before retirement (respectively, child and sexual health, and nursing management) to the CHC, shaping the selection of areas to be investigated and of topics to bring to the council's attention.

Lastly, it is instructive to report another type of rationale for becoming involved although it was mentioned explicitly only by two volunteers. Both Lucy and Paul were well-known within their local communities for being particularly involved in two distinct areas. Lucy was the officer of the local branch of the National Autistic Society (NAS) in Greenshire and was also very active in the dual role of a parent of and sole carer for an autistic girl. Additionally, she was the chair of the Mental Health Greenshire LINK working group. Similarly, Paul, a man with cerebral palsy, was one of the chairs of the local Disability Equality Forum and a facilitator for training on disability and equality issues. He was also a regular attendee of the Self-Directed Support working group in Red LINK, which dealt with social care issues.

Both volunteers viewed their LINK's legal position as more powerful than that of other local organisations they were involved with – Lucy explained that “if a letter is written to somebody, a commissioner or whatever, they have to reply to it so I felt it was slightly more powerful”. When I asked Paul why he joined the LINK, he stated that “it helps for what I fight for, disabled people self-control”. Both volunteers thus associated the legal position of LINKs, and the rights perceived to derive from that position, with the opportunity to pursue their personal interests and ‘fight’ to improve the conditions of traditionally marginalised groups of people (Kitchin, 1998).

Overall, volunteers became involved on the basis of personal reasons, genuine interest in health and social care services, the desire to contribute to and advance their understandings of the health system, and wanting to ensure that certain topics would be considered within LINKs. Salaried members of staff were also key actors in the negotiations of practical decisions in the organisations as well as in PPI. Their backgrounds and views of involvement are therefore presented in the following section.

Officers' backgrounds

The host organisation officers generally decided to apply for a job within LINKs as a result of wanting new ways of pursuing their occupations or to change completely their professional careers. For instance Lauren, the administrator in Red LINK who also facilitated a working group, explained “I thought I'd have a change and go to the health side”; Amy and Nadine, the Research Officer and the Communication and Publicity Officer, were the only salaried employees who felt that their educational backgrounds aligned well with their job descriptions. Also, they had recently attained a degree and, like Amy stated, “were lucky enough to find a job straight out of uni”. Interestingly, all salaried employees I interviewed perceived their jobs as being on “a learning curve” in terms of acquiring understanding of health and social care. In fact, despite believing that some of their skills could be applied to develop the LINK, what seemed to be lacking was specific knowledge of the NHS or the social care system, or both.

When asked about her experience, Helen, a Red LINK development worker, commented:

My background is more around with carers' issues, it's around social care rather than health. So health was a huge learning curve for me because I didn't understand how NHS Trusts worked.

Also Chantal, the Red LINK development worker that replaced Helen, told me "I've never been in health and social care before but I've done community development before so..." Joyce, the host organisation manager, did not view her lack of knowledge about health and social care as an obstacle. Instead, she believed that she had the essential managerial skills to be host manager, and that these were the only skills needed in her job:

This is the first time that I've worked with health and social care [...] because I had managed the family learning project and I'd managed staff and I managed finances and funding, I had that background so when I applied for this post...I don't really need to know about health and social care, I need to support the volunteers that do know.

Her last statement loosely constructed the difference between salaried staff and volunteers in terms of mutually complementary competencies. As we shall see later in the chapter, albeit with some exceptions, this view heavily influenced her interpretation of roles and negotiations of relationships in the course of the work. Here, it is relevant to highlight that Joyce's perspective conflicted with what Arthur, the Red PCT PPI Manager, said in interview regarding the necessary skills that salaried staff should have:

I know it's a different scale entirely, but if you take the House of Commons and the way the Select Committee system works there you've got...researchers who are specialists in their field, briefing the MPs [Members of Parliament] so they can ask, they can question the government from the basis of knowledge...Most LINK members don't have that kind of knowledge and I don't think that LINK staff are specialists in that particularly anyway, so it's probably a reason not to expect that.

In this analogy, researchers would be the salaried staff, MPs the LINK's volunteers and the government the NHS. In-depth knowledge about health and social care was therefore viewed as a crucial asset in constructing a challenging relationship with professionals, wherein roles and responsibilities would be clearly defined. According to Arthur, this lack of knowledge led "to the inability of the LINK to challenge the PCT" and thus, implicitly, an inability to establish relationships where the NHS would consider the LINK as making significant contributions to professionals' work. Although Arthur was the only NHS professional to state openly these sentiments, others suggested that the host organisation should provide participants with information and help them developing the capacity to work constructively. As will be explained in the following section, a good majority of volunteers held similar views. Different understandings of the role of officers affected working relationships, and caused some tension in internal interactions. By contrast, CHC members of staff emphasised the need for them to have relevant experience and accurate knowledge of the health services to ensure that volunteers would be "fully armed to ask challenging questions" as Joey, an officer in Rainbow CHC, put it.

This overview of actors' backgrounds and motivations for involvement frames the discussion on the construction of roles and relationships in LINKs' local arenas in the following section.

Constructing roles and relationships

It emerged, especially from interviews, that actors constructed their roles and developed their relationships based on others' perceived expectations of them. However, the absence of clarity regarding expectations caused tensions and led to vocal discussions within meetings, as mentioned in the previous section. One of the purposes of my study is to explore the interaction of understandings of roles and relationships, and how these aspects in turn affected conceptions of PPI in relation to specific institutional frameworks: as such, I believe all these factors need to be explored together. Previous studies overlap with my subject area, but do not cover quite the same ground and have a distinct focus. For instance, Renedo and Marston (2011) explored how healthcare professionals shaped participants' identities through

their discourses on PPI in a London-based nationally funded project. Hodge (2005) considered volunteers' self-understandings of roles in a mental health forum, but paid particular attention to power imbalances and how these affected the organisation's meetings and deliberations on topics. Lehoux, Daudelin and Abelson (2012) discussed how four participants made sense of the citizen's role in relation to their involvement in a Canadian genetics network although these individuals were the only 'lay' representatives interacting in a professionally-led forum.

The following sections thus discuss the English institutional framework as presented in policy documents describing access on participation and the form this should take, and the ways in which these aspects influenced actors' constructions of roles and relationships.

The view from the top

The set of policy documents published to describe and support the development of LINKs dealt with a range of topics. The discussion document "A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services. A document for information and comment" (DH, 2006) stated that the host organisation will "develop the LINK, recruit members, establish good communication arrangements and support the development and management of a governance structure" (p.16). "Local Involvement Networks Explained" (DH, 2007) similarly defined the host's role as "to support[ing] the LINK to do its work" (p.6), with a focus on setting up the LINK and increasing participation of local groups and individuals. Further, "Stronger Voice, Better Care. Local Involvement Network (LINKs) explained" (DH, 2008) offered another list of activities for "the organisations employed to support LINKs" (p.10), which included "telling the community about a LINK and encouraging people to get involved, advising the LINK, (...) letting the community know about what the LINK is doing and asking for their views, reporting the LINK's progress to Government" (p.10).

Additionally, the NHS Centre for Involvement published a series of guidance documents in 2008 to support various actors' involvement in setting up LINKs. Guide

5 “Procuring a host to support” stated that “the role of a host Organisation is to enable, support and facilitate the activities of a LINK.” (p.2). Such guidance grouped thematically the host organisations’ tasks – administrative and managerial, raising awareness about LINKs and promoting various forms of involvement in the organisations – and provided rather loose definitions of roles and, as a result, ample margins to negotiate everyday decisions.

These policy documents also dealt with the composition of the organisations. “A Stronger Local Voice” (DH, 2006), stated that “how members are appointed will be decided at a local level” (p.16). Interestingly, the choice of terms such as “membership”, “recruitment” and “appointment” echoed the terminology used in the materials on the earlier PPI Forums (Martin, 2008). However, the use of these terms became more ambiguous in the later document, “Local Involvement Networks Explained” (DH, 2007), which mentioned potential “members of LINKs” - such as user-led organisations, local voluntary and community sector organisations and individual people - but it also stated that “you do not have to be a member of a LINK to get involved or have your say” (p.4). Further, the rules governing eligibility to participate were broadly defined - “anyone can be part of LINK” (p.4). “Getting ready for LINKs – Planning your Local Involvement Network” (DH, 2007) provided a glossary in which the notion of member and participant were defined: the former was “a person or a group that make a commitment to take part on a regular basis in the development and implementation of the roles of the LINKs, and to provide information to and collect information from a local community or a specific group within a community. LINKs will decide themselves how members will be chosen. For example, this may be through election from the wider LINK” (p.3). On the other hand, a participant was portrayed as “a person, group or organisation that wants to influence the bigger picture through the roles of the LINK, even though they may not be in a position to participate on a regular basis” (p.3). It is apparent that these top-down definitions may be quite confusing in practice, and the variety of roles suggested offered wide scope for negotiation in view of significant overlaps of tasks and associated responsibilities. “Stronger Voice, Better Care. Local Involvement Network (LINKs) explained” (DH, 2008) declared that “everyone’s views matters” (p.5). In addition to defining who could participate, these documents also defined the

nature of the commitment expected. The same document asserted that “it is up to you how and when” (p.8) to become involved, ranging from “tak[ing] a few minutes to answer a survey” to “becom[ing] an authorised representative who goes to services to see how they are run” (p.8).

This guidance thus set out a fairly elastic definition of who could participate in LINKs. At the national level, the DH did not formally regulate access, as the WAG did, and did not require a standardised threshold of commitment, instead allowing individual participants to determine the extent and form of their participation. The DH’s approach focused on encouraging the act of becoming involved rather than on making rules about how to contribute. As a result, at the local level LINKs could arrange their structure and work on the basis of needs identified by local people, thus encouraging local self-governance. The Welsh framework was much more prescriptive than the English framework (as will be shown in greater detail in the following chapter): for instance, potential CHC candidates had to complete an application form containing a long list of requirements to meet, which CHC members ironically termed a “civil servant job application”.

Given that the policy documents offered loose definitions of individual roles and responsibilities, officers and volunteers were left to come to their own local understanding of what these entailed in everyday practices. In my study most informants defined their roles in terms of what they were expected to do by the local organisations – the discrete tasks that they were routinely expected to carry out, rather than engaging in any critical debate about how the role of LINKs participants could be transformed. In the following section I explore how a variety of actors – such as employed staff, volunteers, NHS and LA professionals - made sense of their roles and built relationships networks in accordance with their understandings of the institutional framework and as a result of practical decisions for managing mutual expectations.

United but disjointed: actors' constructions of roles

Several volunteers expressed a need to receive information from the host organisation officers in order to advance the work of LINKs. Employees were expected to inform regular participants about other working groups' activities and to provide all relevant papers and documents at management group meetings. Helen revealed that:

Participants were very keen on having a member of staff present to be able to support them. It was very much LINK participants wanted staff sitting in the meetings to support them.

The officers concerned would take minutes, record issues to act upon, report decisions, made suggestions on how to develop the work of the group and communicate general information about NHS activities. Their role was largely concerned with administrative tasks, however in practice several volunteers, such as Harriet from Red LINK, also demanded strategic support in terms "of explain[ing] any point of law, anything that is perhaps outside our particular knowledge, that doesn't impinge directly on health and social care". Emma, a volunteer from Greenshire LINK, expected the host to provide "the strategy and the vision", and ensure that they had all the background knowledge necessary to undertake the work. Her professional experience as a former Deputy Regional Director of Nursing for an English NHS body might affect her perspective on this issue. In the following quote Emma provides a telling example:

I can be at a core management meeting and they want to make a decision and I'll ask, I'll say 'Excuse me please, is this meeting quorate? Because it obviously isn't'. And the chair will say [she imitates his voice] 'I don't know', so we'll turn to the manager, our host manager and she will say 'Well I'm not sure, either'...the host should know! If there's a procedure of how the LINK should work, then they should know what they are and they should be advising the chair to say you can't make a decision on this because this meeting is not quorate, but it just gets totally ignored and they make the decision anyway (she laughs).

This extract exemplifies a common expectation across both LINKs: the host organisation was constructed as being responsible for supporting the LINKs' performance of activities through specific information. Joyce's lack of knowledge seemed to clash with Emma's views on how to conduct a meeting and ensure a fair decision-making process. The perceived failure to fulfil this expectation created tensions between volunteers and officers, and had repercussions not only for the development of meetings, but - more importantly - for internal interactions. This may have soured relationships in the long run and undermined trust in employees' abilities. Some participants argued that the host organisation should do or know 'more'. For instance, Sheila, expected 'more' in terms of coordinating volunteers' and officers' activities:

Well, this is the problem we had 'What do they do? What do we do?' And I do take exceptions sometimes to what Joyce has said and I'm sorry to use names, I'll try not to...When we ask her to do something and she says 'Well it's up to you, you do the work', well, I'm a volunteer, I don't get paid, not that that mattered really, I'm doing it because I have a reason to do it and that's got nothing to do with the payment, but there is a sort of difficulty in knowing what they do and what the volunteers do and this is, I think, to my mind, one of the disadvantages of this organisation: that has never been made clear the lines of, you know, who does what. I know if we ask her to do something then she does it, but I think there should be something else, a structure...

Her tone conveyed a combination of frustration and resignation. She identified the absence of a formal role structure as the main flaw of the organisation; based on her interview as well as analysis of my observational data, this flaw is constructed as deserving particular attention due to the strain it placed on relationships. This lack of shared understanding was not openly discussed or resolved, but rather was indirectly expressed through subtle disagreements and, often, through non-verbal communication as well (such as puffing, eye-rolling, and/or visual disengagement from physical surroundings). Further, Sheila drew attention to the distinction between volunteers and officers, whose symbolic meaning is relevant in discussing negotiations of roles. The overall sentiment was that, as volunteers could only dedicate a certain amount of time and commitment to the LINK, they should receive

all the support needed, and the organisational structure should facilitate and simplify their activities. It appears as though definitional ambiguities produced additional work for participants, who not only had to carry out the duties of volunteering but also had to invest time in making sense of how the LINK functioned and in working out roles.

A general lack of knowledge about what other working groups were doing was broadly reflected in several volunteers' claims that "I don't know what's going on" or "that person could tell you more about it". Sheila expressed the hope that the new LHW would actually

Cut down on this sort of lack of coordination and communication, it would be more integration and it would show that we were an organisation that can work together in all the various...groups, tribes whatever you wanna call them mmh [she smiles sarcastically], because we're a bit tribal.

In the extract, she traced back the fragmented nature of the LINK to the early days of the organisation and drew an analogy between the working groups and "tribes", suggesting that volunteers had not taken time to reflect on what LINKs could do and how they could do it, due to a general attitude that she described as "we gotta get started, we got to make a start, we got to show something for our existence". The perceived pressure to produce evidence of impact or success is a key aspect of LINKs and CHCs, both for the general work of the organisations and for PPI in particular, which led to the construction of such policies mainly in legal terms (see Chapter Six and Seven). These examples offer some points for reflection. Questions may be raised about what kind of evidence of good work would be recognised and accepted by a plurality of stakeholders with different roles and expectations (Wells, 2007). In part the need was to show that the LINK was making a positive difference in line with the idea that "what counts is what works", a dictum introduced by the Labour Party in run-up to the 1997 general election². Such an approach may create pressure on voluntary groups to find evidence of good working practice that meet institutional requirements. But this may be at the expense of the quality of deliberation on how to

² Labour Party Manifesto (1997). *New Labour because Britain deserves better.*

produce that evidence or on what would benefit the LINK in the long run rather than the present.

Salaried staff made several efforts to strike a balance between their understandings of roles and volunteers' expectations. Discussions with officers revealed that one of the rhetorical strategies that they employed in an attempt to act appropriately upon perceived participants' desire was to declare that "the LINK is theirs". In practice, as reported by Sheila, this meant that Joyce and other officers tended to encourage volunteers "to do the work" themselves in order to foster a sense of ownership of said work. Interestingly, most of the regular participants interpreted these actions as increasing their workload and thus increasing related pressure. However, the line of demarcation between roles was context-dependent and negotiated ad-hoc according to the topic discussed. In fact (as we shall see in Chapter Seven) volunteers never raised objections to the fact that the development workers' decisions on PPI were mainly based on their personal evaluations rather than on-going discussions with participants. Officers worked hard to support volunteers, but had to deal with a strong sense of ambiguity and they were not always sure where their responsibilities began and ended. As a result, in practice, they often seemed to resist the construction of their roles as purely administrative; this was evident in Joyce's interview when she described the relevance of the White Paper "Equity and Excellence: Liberating the NHS" (DH, 2010) to LINKs and how she believed they should act upon it:

I was hoping that they [volunteers] would say 'Let's do a consultation!' but they haven't, so I should be saying it again at the next management group in a couple of weeks...I am trying to get them, you know, to really take it on board, that this is something you know they need to be thinking about...if the LINK is going to survive and move forward...And it's almost like....well, is it my place to push them? But I think I should! [she laughs]

This quote seems to conflict with the principle that "the LINK is theirs". However, Joyce based her 'push' on her strong belief that there was scope for her to offer a more pronounced type of support to volunteers. The 2010 White Paper represented a significant moment for LINKs in relation to the proposed changes to the organisation, and Joyce sought to encourage volunteers to reflect on the new framework and how

it would affect local arrangements. Here the distinction between officers and volunteers seemed to disappear in light of the former's interest to open up spaces for reflexivity, and it was hard to believe that officers were undermining participants' authority in decision-making processes in similar circumstances.

However, the roles of employees and volunteers were sometimes viewed as complementary parts of a common strategy to move the LINK forward. For instance, Ken's distinction between volunteers and the host organisation portrayed the latter as a valuable resource for LINKs:

Because they're paid, they're committed full time or at least part-time anyway, whereas the rest of us are volunteers and we're trying to sort of fit our involvement into the short time we have available to get things to happen, often trying to get them happen involves sort of long involvement, so you know people need to work for several hours and as a volunteer you don't always have that. So I think it's been a real bonus to have a host organisation.

Ken's view seemed to emerge from his conception of voluntary work, as something that "fit[s]" into one's daily life rather than constituting a central part of it. Sometimes volunteers might have had quite frequent contacts and interactions with officers (as happened for most regular participants in the management groups), and this might result in greater requirements for support, especially if the individuals involved have similar responsibilities to those of chairs. Ken did not question the roles and responsibilities attached to employees: in fact, it seems that the only difference he perceived between the two groups was the different amount of time that the two groups dedicated to the LINKs. One reason why his view differed from the vast majority of volunteers' perspectives may have been related to his occupational status (he was still working full-time as a project manager and only had Friday afternoons off), which therefore limited his involvement with the LINK to very few activities. Perhaps individuals involved more intensely may have more opportunities to develop critical opinions and attach different meanings to organisational roles; in addition, Ken was at his first experience of participation, and as such he may have been more flexible about the type of support needed.

Interestingly, members of staff also mentioned problems in working out roles in practice. Joyce reported a scenario similar to that described by Sheila:

We are here to support them [volunteers] to do the work, but we're not here to do the work for them. So it may mean that we send out letters, do emails for them, write up anything that...you know, the reports that they want us to write up. But it's their work, you know, they're the important ones. We're just there to facilitate whatever they want the LINK to look like.

The lack of a formal organisational structure which actors could refer to when interacting and planning their activities suggested that negotiations of roles occurred simultaneously with LINKs' daily business. In several meetings I observed, participants needed to negotiate their roles in the course of discussions about LINKs work, rather than as a separate activity, thus diverting attention and precious time away from decision-making processes. In other words, actors had to balance time between negotiating responsibilities and advancing discussions on issues that LINKs could deal with, and relationships with the NHS.

The fluidity of role improvisation and the ambiguities attached to the process were reflected in Nadine's comment: "It'd be a much easier working relationship if sometimes I knew what they wanted from me! [she laughed and blushed]". Her anxieties in dealing with her role and with volunteers were made visible within meetings through her non-verbal behaviour. I noticed that she frequently turned towards Joyce as though seeking her visual indication of support when she was talking or facilitating the meeting. Similarly, Amy appeared uncomfortable in meetings and would always sit near her colleagues, as if she felt the need to bunch together against possible opposition. One reason for Nadine and Amy's discomfort may have been the considerable age-divide with volunteers, who were generally adult or retired people, whereas the two officers were in fact in their early twenties. This difference in age may have prevented Nadine and Amy from arguing against or reproving those volunteers.

In an attempt to negotiate clearer understandings of roles, the host organisation conducted a survey in early 2010 in order to explore volunteers' views on the nature

of support provided and expected. In interview, Joyce reported what they learnt from the survey:

Generally there was a breakdown in communication but the LINK participants thought that we should be doing everything and we were able to explain to them that that's not our role... Because every group that we facilitate, you know, we get asked to do an awful lot of work and some of the work we can do on behalf of the participants, but sometimes you think really, they could be going away and doing that themselves. So it's a hard line to define our role and what's theirs and we're just trying to be supportive, you know, in the time that we've got, to be supportive as we can for the participants. But sometimes they'd like us to do a lot more [she laughs].

Most members of the host organisation shared Joyce's reasoning. She highlighted a pattern that was evident within interactions: despite officers' willingness to support volunteers, and ensure they were doing all they could to assist, volunteers seemed to misinterpret their desire "to be supportive". Salaried staff appeared to act largely on the basis of common sense and experience, rather than on a formal description of fixed roles detailing the tasks that needed to be undertaken. They were genuinely concerned with ensuring that participants could contribute and do the work they wanted. At a more general level, their views were shaped by DH guidance (2007) requiring the host organisation to "give practical support to keep it (the LINKs) going" (p.5). Joyce also declared that the survey did not achieve a very high response rate and was only administered in Red LINK because "in Greenshire LINK there's much more understanding that they are there to do the work and we are there to support them to do it". However, my observational data and interviews show that some Greenshire LINK volunteers (such as Emma, see p.70) reported exactly the same issues surrounding the role of officers as those presented earlier by Red LINK volunteers. Joyce's view of how the host organisation was perceived within the two LINKs may have been based on the animated – and sometimes heated - discussions that occurred within management group meetings, and, more importantly, on how they were managed and resolved by the Chairs. Quarrels were less frequent in Greenshire LINK and its Chair, Gary, tended to intervene and mediate between the parties involved, and would conclude the discussion by refocusing the meeting on the agenda for that day. On the other hand Sebastian, the Red LINK Chair, allowed the

discussion to run its course. This sometimes resulted in lengthy unmediated discussions, which had to be terminated due to time constraints.

Salaried staff added that at times they felt overwhelmed by volunteers' requests for assistance. Rachel, Greenshore LINK's administrator, stated that "some participants see myself as their PA", and Helen also explained that:

Sometimes some participants think that perhaps the host should...run the LINK rather than participants, whereas as the host we think that the participants are the LINK! There are other participants who see it very much as their own and probably think that we're interfering too much! So it's quite tricky, really.

In practice though, the separation between these two groups of volunteers was less sharp than those Helen described in interview. Meanings and perspectives concerning the role of officers were not set in stone and were related to specific areas of interest: for instance, Chapter Six and Seven will show how most volunteers were happy with members of staff taking the lead on PPI. However officers tended to refer to themselves as 'we' whereas participants would be described as 'they'. In this way, staff distanced themselves from volunteers as a means of reproducing the distinction between the two groups. Paradoxically, the host organisation officers needed to reinforce their boundaries in order to 'protect' themselves from potential volunteers' claims concerning the lack of understanding of roles. In practice, though, salaried staff often struggled to maintain this strict distinction: as mentioned earlier, they had mixed feelings regarding what their role entailed in practice. They were nevertheless part of their LINKs and as such seemed to have a strong sense of attachment to the organisations. The nature of this controversial issue may be exemplified in salaried staff's views of LINKs as organisations. At times it was not clear whether they were referring to the LINK as a whole or to themselves as part of the host organisation. This confusion can be seen in Joyce's view on the institutional position of LINKs:

The LINKs because we're not part of the Trust and we're not part of the LA, we're within Sunflower, we've got an independent voice.

Here the pronoun 'we' constitute the LINK as a unity of volunteers and host organisation, which stands in strong contrast to the neat distinction presented earlier,

wherein ‘we’ and ‘they’ clearly referred to the host organisation and volunteers respectively. A similarly ambiguous use of pronouns can be found in the following extract from Beth:

We might hold an event or we might attend an event [...] I think we...yeah I think I'm gonna start some of the things I want to do in this sort of year - I want to because obviously we haven't got the funding for our newsletter this year but I want to have a piece in some of the local newsletters. X newsletter is received quite well and if we kind of use that as a vehicle then hopefully we'll be able to promote ourselves better.

Here Beth was describing what the LINK was actually doing when trying to engage with patients and members of the public. The shift between “I” and “we” is reflective of the pragmatic difficulty of acting upon a theoretical distinction and maintaining it over time.

Volunteers’ negative perspectives on how officers embodied the role of support framed interactions between the two groups. For some participants, dissatisfactions with LINKs could be traced back to their participation in previous PPI arrangements, which was positively constructed as a model against which the LINKs failed to measure up. These past experiences appeared to weigh heavily on current understandings of roles and responsibilities. For instance Andy compared the type of support provided within PPI Forums by a support organisation (SO) to what they received within LINKs:

There is no support really, locally, and perhaps this is confidential to you, there's little support and in fact there isn't really any support for providing us with information. But the support organisation, the previous server provided all this information so when we met we had details, we had reports, we had journal abstracts, we had press reports, you see, from the previous months...Somebody did the press cuttings so we would know if there was a concern in a certain area of the community on the acute hospital.

Andy identified the quality of assistance provided as a factor heavily affecting volunteers’ capacities to make contributions through the LINK. The SO collected detailed information in the form of documents and media reports, which constituted

the evidence that participants could use to plan their work and to identify local concerns. The SO represented an ideal model of support, which empowered the PPI Forum in terms of “anticipat[ing] things and reacting to them”, as Andy put it. However, he explained that such support “doesn’t happen here” in LINKs.

Other volunteers also viewed the host organisation as being intrusive and too proactive in making decisions. As mentioned previously, however, the perspectives on officers’ role, were flexible and subject to be altered in relation to the areas of concern. Broadly, the underlying assumption was that officers sometimes made decisions without involving or consulting volunteers. Since DH guidelines (2007) describe the role of the host as supporting the LINK by providing a general activities list, we can see how this definition may be subject to various interpretations according to different circumstances. As Tyler, a volunteer in both LINKs, explained somewhat resentfully:

The host organisation has undertaken work that the governance committee haven't actually said yes, okay to do that, and they've presented reports not in the name of LINK but because they undertook the work themselves and they weren't actually asked to do that work.

The quote provides some points for discussion. Both LINKs had governance groups in charge of regulating the internal functioning of LINKs and monitoring the distribution of the budget across the various areas of the organisations. Furthermore, these groups were also responsible for approving and/or suggesting internal reorganisational changes. Volunteers may have felt that their decision-making authority was threatened by the perceived inabilities of officers to respect the boundaries of their role. They viewed themselves as naturally entitled to be in control of the LINK, and employees were only meant to enable that process and not influence it. In an illuminating interview, Daniel, a Red LINK volunteer, discussed the symbolic importance of language in shaping role construction:

The LINK's host manager, Joyce...For months and months she called herself the LINK's manager...and I said 'You're not the LINK's manager, you don't manage us, you are the manager of the support staff. You're not our manager, you're not our boss', and in the end she changed her title to LINK's host manager which is what she

is. But you understand [...] they are our servants...Seriously I mean it's not a derogatory term: there are masters and servants and we are the masters, they are our servants. And it was quite clear with the [PPI] forums.

In the above extract, Daniel highlighted a controversial issue. He reports trying to adjust the role of the host organisation in the LINK's regular work by asking Joyce to modify her self-presentation, which supposedly reflected her understanding of her role. As Becker and Carper (1956) emphasised, "occupational title[s] carry a great deal of symbolic meaning, which tends to be incorporated into the identity" (p.342). Daniel viewed Joyce's selection of language as potentially legitimising an erroneous conception of her role, and hence openly characterised her job title as incorrect in an effort to rebalance and reframe roles. The hierarchy of the "masters and servants" analogy enables us to set the framework for examining the relationship between volunteers and officers. Although a hierarchy can establish both vertical and horizontal links, it seems sensible to argue that here the phrase refers to a vertical relationship, wherein officers' roles should be confined to serving volunteers in the activities they decide to undertake. Similar to reports from other volunteers, Daniel's view was strengthened by his experience with PPI Forums, wherein the SO staff reportedly acted as the volunteers' servants.

NHS and LA professionals constituted another group of actors that contributed to role constructions within LINKs. Generally, they attributed a crucial role to the host organisation in terms of supporting the participants: officers were expected to be "stronger", "more directive" and "skilled". As illustrated in the section discussing employees' backgrounds, Arthur bemoaned the lack of in-depth knowledge about health and social care. Both volunteers and professionals thus agreed broadly that the support provided was not appropriate, although they framed this within different contexts. For professionals, support meant empowering volunteers to build effective relationships with the NHS. Arthur declared:

Some discussion I've been in LINK frankly...I could have got as much useful discussion about going to the local pub and saying 'What do you think about the health service?' It would have been the same level, it's pretty general, it's pretty anecdotal and it's not adding a lot of value.

He viewed the role of salaried staff as crucial to enabling the LINK to improve the quality of the discussions and bring them up to the expected standard, and to contribute meaningfully to the NHS work. He also contested the use of newspaper cuttings within meetings as sources of information, which he saw as failing short of the standard that volunteers were expected to employ in interactions with professionals. However, as noted above, Andy endorsed the use of media cuttings to promote discussions and to identify local concerns. The nature of these oppositional views was another key element in constructing relationships: professionals' perspectives were strongly embedded in an evidence-based culture which socialised them to produce work drawn on quantifiable and standardised sources, which in turn constituted the grounds for future activities. Professionals constructed volunteers' and officers' roles based on what they expected to receive from collaborating with LINKs – namely, sound evidence to inform their commissioning cycle and the delivery of services. Broadly, then, the host organisation was responsible for empowering volunteers, complying with professionals' demands to produce evidence and transforming the LINK into the body the government wanted it to be.

In turn, professionals regularly involved with LINKs viewed their role as mainly consisting of liaising with the NHS and the organisations, facilitating communication and providing the NHS with constructive work informing strategic decisions on resource allocation. They also represented symbolic actors reminding the NHS that PPI was a legal requirement: professionals had to consider the LINK as one of the channels through which patients and the public could be involved. In turn, professionals' expectations of volunteers varied significantly. James and Kate, two professionals from the LA and the NHS who regularly attended Greenshire LINK's meetings, viewed volunteering as primarily motivated by individuals' interests, the very nature of which could determine volunteers' degrees of involvement and the types of activities undertaken. Kate expected the LINK "to keep us informed with what they're doing", while James listed his expectations of volunteers' skills as "being constructive, get[ing] a broad range of views, speak[ing] authoritatively on behalf of the LINK, and being able to effectively challenge us". He also added that "ideally [volunteers] are there to raise the issues from a different perspective than has been considered by everybody else around the table". This last expectation was very

similar to how Leigh, a professional Blue Sand Hill LHB who regularly attended CHC meetings, constructed the role of CHC members: “the third person in the room opinion [to] make it clearer for people”.

Arthur had clear expectations regarding the nature of volunteers’ contribution in shaping NHS services. In interview, he recalled:

I witnessed in some of the group discussions people who, well, for a range of reasons, because they have mental health problems or all sort of things, actually their contribution isn’t particularly valuable [...] I think for some people put in some contexts, that’s not fair to the person because they’re never gonna make that contribution and there’s a bit of collusion going on there - I mean, you know, collusion can be easier than challenging.

In this example, Arthur constructed volunteers’ roles on the basis of established definitions of who could make a meaningful contribution, and what it entailed. Specifically, individuals with “mental health problems and all sort of things” were viewed as incapable of providing the kind of input considered relevant from professionals’ perspective and that could inform the commissioning process.

These expectations constructed volunteers’ roles in opposition to DH guidelines on LINKs (2006, 2007, 2008, 2010). For instance, the 2010 document “Help Shape Your Local Health and Social Care - Your guide to Local Involvement Networks (LINKs)” emphasised an inclusive approach, stating that “Anyone can join a LINK. Everyone is welcome, and everyone’s opinions matter” (p.3). The apparent tension between everyday practices and policy documents, in combination with actors’ backgrounds and rationales for involvement, highlights the situated and interactional nature of role improvisation.

With this established, we now turn to explore the construction of relationships amongst actors and how these were shaped by the guidance and practical expectations outlined in the preceding sections.

Constructing relationships

As a consequence of ambivalence and uncertainty about roles, actors struggled to negotiate relationships. In my observational data, I recorded several instances when volunteers were critical of the host organisation. The atmosphere in some meetings could be quite tense, and I personally experienced it in several occasions. Additionally, discussion of specific issues was sometimes concluded prematurely (Hodge, 2005) as a way to re-establish an ordered environment. The following extract from my fieldnotes reports an incident which occurred between Joyce, who was facilitating the Older People group, and Harriet, acting as Chair. In the middle of the meeting, a woman from Tulips (a partnership between various local stakeholders aiming at improving services for older people), who was attending a LINK meeting for the second time, posed a question:

A woman from Tulips asked "Are toilet issues like lack of public toilets, bus passes and foot care appropriate issues to be discussed here?" Harriet said that they usually go to the Older People Forum. Joyce intervened and clarified "We don't duplicate what the Older People Forum does". Harriet remarked "We have to keep up with what's been going on in this area". The woman asked again "So these three issues I mentioned won't come here because they've been already discussed at the Older People Forum, right?" and Joyce said that was right. At that point Harriet, who looked quite irritated, firmly said "It depends on what they are Joyce". I knew that tone very well – it expressed all her disagreement towards the host manager's interference. When I turned to Joyce, she was staring at her papers and didn't add anything else. Then she looked at the woman, raised her eyebrows and smiled, like she was saying "That's it, that's what she says". Nobody spoke, and then they moved on to the next item on the agenda.

This episode exemplifies a typical organisational conflict. Harriet seemed to contradict herself: she first suggested that these issues fell under the purview of the Older People Forum and then, when the participant from Tulips tried to check the position, she asserted her authority as chair in an attempt to limit Joyce's intervention. Harriet may have felt threatened by Joyce and feared that she was



losing control over deciding what issues and concerns the group would deal with. Similar instances were quite recurrent in my fieldnotes.

Disagreements about roles were amplified by a lack of personal bonds between officers and volunteers. Generally, salaried staff arrived at meetings about ten minutes before the starting time, and left immediately afterwards. This left them very little time to engage in casual conversations and build stronger personal relationships with volunteers. When LINKs met at Sunflower's, where the host organisation was based, and there were two consecutive meetings before and after the lunch break, officers usually headed back to their office during the lunch break and returned to the meeting room just in time for the second meeting³. Additionally, given officers' perceived lack of detailed knowledge on health, social care and LINKs' operational practices, volunteers struggled to develop a sense of trust in the role of the host organisation, which clearly did not help in building collaborative relations (Wharton, 1991). Martin and Finn (2011) discussed "informal opportunities" (p.8) as a means to establish trust within multi-professional health care teams. Informal talk could help to build a sense of familiarity and to expand information on individuals' personal stories which, in turn, would support the development of trust. Although an in-depth analysis of the concept of trust and its role in organisational dynamics is beyond the scope of this study, we can easily draw a comparison with CHCs, where Rainbow CHC officers, for instance, arrived at meetings' rooms at least forty-five minutes prior to the starting time, then welcomed members and engaged in conversation with everyone. Similarly, after the meeting people engaged in some discussions about it, and officers were willing to give lifts to volunteers on their way home. These two set of strategies shaped interactions differently over time. In addition, I never observed instances where members felt the need to 'protect' their authority within CHCs: rather, volunteers were actually willing to be advised (and led) by officers. The Welsh context thus amplifies the bearing of trust in facilitating interactions and removed potential sources of tensions. As we shall see in the next chapter (where I will also examine the extent of difference between the selected CHCs), members did

³ Once I was invited to join them and accepted because I thought it would be a good opportunity to familiarise with officers. However, I reasoned that volunteers might have seen me as allied to employees and that might have affected negatively our relationships. As a result, I declined Joyce's invitation in another occasion.

not question the fact that some decisions were made by staff due to an unconditional trust in them, both as individuals and as professionals.

In addition to creating a complex network of relationships between salaried staff and volunteers, LINKs also interacted with NHS and LA professionals to facilitate better collaboration. Many participants took the legal framework as their starting point for thinking about the relationships that LINKs should build over time. Interestingly, many volunteers and staff grounded their arguments concerning their right to interact with the NHS and LAs on two key sources, namely the Local Government and Public Involvement in Health Act 2007 and the NHS Constitution (2009), although they did not provide further details about the actual content of the documents.

During meetings where only volunteers were in attendance, they complained and expressed reservations about the extent of the assistance that NHS professionals gave. However, I never observed volunteers making negative remarks directly to NHS professionals, and despite a few attempts to oppose professionals' behaviours, participants generally appeared to accept their attitudes and the way they interacted with LINKs. The most likely explanation for this is that LINKs were keen to build long-term working relationships with the NHS and its representatives although in practice this meant that volunteers made informal decisions on who could interact with NHS professionals, and how this should be done. Sheila admitted, for example, that she was careful in her selection of volunteers for 'enter and view' visits: I will expand further on this point in Chapter Nine by discussing how LINKs interacted with professionals in relation to PPI. For now, it is sufficient to highlight that volunteers constructed their roles in ways that offered meaningful contributions and portrayed an ideal image of LINKs as the organisations that the government wanted them to be, and that NHS professionals expected to collaborate with. This process resembles what Goffman termed impression management (1959), a strategy employed to shape and control the development of interactions with significant others. This interpretation is further supported by the fact that volunteers considered the Freedom of Information Act as a sort of emergency tool and generally avoided its use, which they felt could compromise relationships with the NHS. Informal inquiries would be made through emails and phone calls before any official request was made.

Furthermore, volunteers appreciated the mere fact that professionals attended the meetings. They acknowledged professionals' heavy workloads, and thus attached a powerful symbolic meaning to attendance as a means of building relationships. This construction may have led to a lack of reflexivity about the real contribution professionals could make; moreover, volunteers did not appear to question the broad context within which professionals' participation materialised. Apart from the very few NHS and LA actors who regularly attended LINKs' working groups and acted as interface between the two organisations, other professionals were sometimes invited because their role was relevant to the issues currently discussed or because LINKs wished to undertake an activity that required professionals' collaboration. In the majority of the latter cases, drawing on my observations, I soon realised that professionals had indicated to officers the approximate time that they would be able to join the meeting (the latter would then report the information to people in attendance), and the agenda and its actual development would be adjusted to these requirements. They would usually leave immediately after the question-and-answer session following their presentation. To the best of my knowledge, volunteers never questioned this attitude, which may have led to an uncritical acceptance of the extent of professionals' co-operation with LINKs.

The section has highlighted the extent to which actors' improvisations of roles were closely intertwined with organisational relationships and understandings of LINKs' work. The following section provides an insight into volunteers' understandings of their personal attributes as framing their involvement in LINKs and shows how they differentiated themselves from others to create a sense of uniqueness regarding their role.

The ideal model of volunteer

As illustrated previously, DH guidance gave considerable discretion to local actors to decide who would make up the LINK, rather than containing prescriptive regulations. "Everyone is welcome" somehow became officers' mantra, which Arthur and Charlotte (another PPI Manager in an NHS body in Red City) reformulated as "the open door policy". Perhaps as a consequence of this lack of a clear framework,

volunteers progressively constructed a layer of informal understandings about participation, which were mainly concerned with the nature of the contribution expected and with the participants' ability to act in the interest of 'the public' and look at 'wider issues'. These constructions contained inter alia ideas about the need to balance personal motivations and a wider interest in, or knowledge of health and social care, which, as outlined previously, constituted volunteers' main rationales for involvement. Participants viewed these as the key features of their role, and good motivation and knowledge of the system were increasingly mentioned in their talk as necessary qualities for doing the work. The idea that volunteers needed more than a purely personal interest in some condition or service was consistent with professionals' emphasis on the need to act upon "trends" or issues rather than specific cases or events; therefore the NHS and LA also played a key role in reinforcing such a construction.

Volunteers might be viewed as actors who negotiated the meanings of LINKs' work, and the roles involved, and who in effect began to create barriers to access for people who lacked the expected characteristics for participation. Although in theory participants could not restrict such access or remove individuals who did not adhere to their model of the ideal volunteer, they developed ways of encouraging those with the desired characteristics. Occasional participants with particular skills and knowledge who were potentially able to become regularly involved because they showed great interest in volunteering were usually encouraged to participate regularly. I also observed Sebastian insisting on offering travel expenses reimbursements to non-regulars participants who had key roles in the communities (such as the chair of a local Somali group and an advocate working for a mental health charity) and showing particular appreciation to them for donating their time.

It seems as though this selection of new volunteers was based on the degree of compliance with internal understandings of roles which, although informal, held normative value for the regulation of working practices. Interestingly, there appeared to be a paradox within participants' constructions of the ideal volunteer: while most of them had become involved on the basis of passion and personal interest in health and social care services, these were viewed as negative attributes in potential participants from the general public. Individuals unable to distinguish between

individual and public interest were automatically labelled as “single-issue people”, people having a “personal agenda”, being solely “interested in their own little patch”, or a “pressure group” with “a vested interest”. The nature of the public was constructed differently, but always in opposition to volunteers’ self-understandings of their own roles, as shall be explored in Chapter Five. As Sheila put it:

I mean I've got a particular interest why I joined LINK but I don't bring it up at every meeting, I don't bring it up all the time. I realised that it's one of many issues and... As long as we keep an eye on it, whatever it is, that's all I think I'm entitled to. It's one of many issues with our business with the trust.

As we have seen, several volunteers were motivated by personal experiences and particular interests in the services, yet viewed themselves as having the ability to distance themselves from their own passions – an ability that (in the view of insiders) the partisan individual lacked. LINK volunteers viewed this as a concern insofar as personal issues could hijack a meeting and restrict opportunities for other people to receive information and ask professionals relevant questions. This is depicted in the following extract from an interview with Luke, a volunteer in Greenshire LINK:

The decision on X Hospital for example [...] I was heavily involved in it [...] What I found out from that consultation process was that it was dominated by single issue groups. People will come along with their particular issue that they wish to follow up; they asked for information, they were given the information, they took notice of the information, kept asking the same questions and they were actually very obstructive in the sense that... Well, they were not constructive, let's put it this way, and not constructive in a sense that they didn't listen to and properly interact - and it wasn't the people on the statutory side I blame for the long time it took to consult, but the people they were consulting with.

Salaried staff reminded participants, particularly the regular ones, that DH guidelines expected LINKs to be inclusive. For instance, Joyce's motto during meetings was “Anyone can join the LINK, and people are free to give us as much or as little time as they can”. Although in theory some volunteers may have agreed with such a statement, in practice this was a contentious point around which a great deal of discussion about responsibilities tended to develop. Not respecting such an

expectation could pose practical challenges to the development of discussion, as Luke reported above.

Another way in which LINK participants constructed the attributes of volunteers as unique was the use of the term work to label involvement (compare: Blackstone, 2009); this also happened within CHCs. The use of this term may be viewed as an attempt to 'upgrade' the status of volunteering by linking it to the requirements of paid work: responsibility, specific skills, decision-making abilities, accuracy, teamwork and professionalism strengthened the sense of uniqueness related to volunteering. This definition was also supported by the considerable volume of documents that volunteers were expected to read and understand. The idea of 'doing work' was also embodied in CHC members' comments on the quantity of time they dedicated to the organisation: Sally, a member in Rainbow LC, once told me "I was up 'til late last night to do the work". Similarly, LINK volunteers presented themselves as very busy.

LINK participants were people who worked hard and were committed to the responsibilities attached to their involvement. We will see in the next chapter how this aspect was even more amplified within CHCs. Common sense suggests that volunteering is carried out in one's spare time and is an enjoyable and rewarding activity, rather than a burdensome task or a source of emotional tensions. However, some individuals emphasised the negative connotations of involvement: having "too much to do" was also viewed as a consequence of not having sufficient current volunteers 'doing enough. This was the primary reason why Sheila stepped down as a chair of a working group: she explained that she "just needed a break". Similarly, Harriet complained that they needed additional people committed to undertake the organisation's tasks. This heavy involvement appeared to prevent some people from enjoying volunteering, which became an unpleasant job rather than the fulfilment of a desire to contribute to health and social care services. Despite the DH guidelines stating that "it is up to you how and when you participate" (2006, 2007, 2008), LINK participants generally viewed their activity as a commitment that entailed a significant and consistent input of time and effort.

Against this background volunteers formed understandings of their roles as unique and progressively distanced themselves particularly from members of the general public. There was a kind of definitional divide whereby participants constructed images of 'the public' as an entity which shared few of the characteristics of LINKs insiders. I will examine this aspect in Chapter Five.

In the next section, I will reflect on the concept of network as the form of organisational arrangement that was central to the establishment of LINKs, and I will also examine how volunteers made sense of it in everyday work.

The concept of network in PPI

The key points discussed in this chapter lead into an examination of the concept of network as the organisational structure for LINKs. As we have seen, in principle LINKs were distinctive for their openness and inclusiveness. We can thus argue that they could deal with any possible topic within the remit of health and social care, that anyone had a right to talk and be listened and, most importantly, that 'everyone's views matter'. In practice, actors' decisions shaped established understandings of participation, the requirements to fulfil and the nature of commitment for volunteers, and themes for discussion in their own image. Mullen, Hughes and Vincent-Jones (2011) had anticipated an issue in relation to the adoption of networks - namely, that it "may lead to concerns about inclusivity (for instance, if *de facto* decision-making tends to rest with a few participants)" (p.30). In fact both LINKs established management and governance groups whereby a limited number of participants were responsible for making key decisions that affected the development of their work. These groups represented the socially constructed 'centre' of LINKs and volunteers' attempts to make sense of a new imposed organisational structure by mainly drawing on traditional participatory forms that they experienced in past PPI arrangements or other voluntary organisations.

Further, in an echo of the findings of Martin and Finn's (2011) study on pilot cancer-genetics projects, volunteers frequently lamented a lack of direction from the DH: for

this reason, a high proportion of volunteers expressed the opinion that “LINKs were set up to fail”.

It must be noted that it was particularly difficult for some individuals with experience of previous PPI arrangements (PPI Forums and, in some cases, CHCs) to operate without a formal organisational structure that regulated, for instance, the appointment of members, which was one of the aspects that participants missed the most. Interviews with volunteers who had been members of previous PPI bodies clearly demonstrated the interpretive tension between the past prescriptive framework and the new flexible network arrangement. Andy, who had experience of both CHCs and PPI Forums, defined committed volunteers as individuals “who don’t just flit in and out for the whole meeting, which you’ve been interviewing, and that have been involved for a number of years”. He set up a contrast between the average participant - who reflected the DH’s ideal of inclusiveness and flexibility - and volunteers like himself who still complied with rules and working practices from previous arrangements, such as CHCs and PPI Forums. Andy viewed the interview process as guaranteeing the recruitment of reliable volunteers to undertake the work of LINKs. Similarly, Harriet strongly declared that

It should go back to the old Community Health Councils. People were interviewed and when they came in, they knew they were going to do this type of work and they were committed to doing it...they didn’t just come to meetings and sit down, eat a few biscuits and then go away again...and I’m sorry, but we have got a number of people here that do that and run up the expenses at the same time, it’s a waste of money.

In this extract, she constructed the role of the volunteer’ in relation to her understanding of the form of participation required (i.e. regular commitment to advance the work of the LINK), and also made sense of the concept of network based on previous CHC procedures. Reminiscences (and nostalgia) of former experiences were also visible in the use of terminology: volunteers sometimes referred to their peers as members rather than participants, although salaried staff usually suggested that the latter term was more suitable to the role of LINKs and consistent with the underlying philosophy of networks. Interestingly, old volunteers reported that a

formalised organisational structure represented a means of recreating a system that would control individuals' performances. Michael, a volunteer in both LINKs, elaborated on this in interview:

Because it's not a public appointment there's no threat of removal, and that's where I think is a great let-down to LINKs because...I'm not appointed...And if I was appointed by some form of process...Then there could be an assessment to make sure that I actually do what I was there to do...And that's why and that's where I think the PPI [forum] worked but the LINK hasn't.

My data suggest that volunteers attempted to recreate PPI Forums or CHC social processes within a structure of a different nature. By contrast, in line with DH guidelines, officers viewed the LINKs as “a loose network of individuals and community groups”; in addition, as previously noted, Joyce often declared that “people can give us as much or as little time as they can”. At the same time, it transpired that volunteers placed a great emphasis on the belief that consistent time commitment was an essential prerequisite to enable the enactment of the role of the ideal participant. Again, this could be related to volunteers' past experiences. As I shall examine in Chapter Four, the volunteering position advertisement for CHCs, for instance, stated that members were required to be involved with the organisation for three to five days a month: in practice, LINKs' informal structure operated along similar lines. Michael gave an enlightening account of how old volunteers attempted to replicate a managerial structure that would reflect and maintain the perceived degree of knowledge and capacity experienced in CHCs and PPI Forums:

They [the DH] didn't put a structure in place - I had to kind of create one. I had to fight down hard to get it, which basically said that the old PPI group would form the part of the management group and then there would be some form of election. I mean, we've been quite lucky in having a management group that is sufficiently skilled but...If we hadn't been careful, we wouldn't have had one that was that skilled and that was found basically in an imposed...elected...non democ...you know, Chinese style appointment system!...Which has worked to the benefit of stability. I mean, I'm not a communist!

This extract indicates that volunteers managed to construct the core group of the organisation in order to guarantee that the people with decision-making powers had what was considered requisite knowledge and skills. Although nobody in Greenshire LINK explicitly reported such a strategy, several volunteers previously involved in PPI Forums were also members of the core group and Chairs of working groups, and might have deployed an organisational structure and working practices similar to those developed in past arrangements. This argument is further substantiated by the presence of a common host organisation, which may have supported similar negotiations in both LINKs. In the next chapter I will show how CHC officers, especially in Rainbow CHC, devised a similar strategy to build the organisation in their own image. The ad-hoc construction of LINKs can be further seen in the development of meetings, which from the early days of the organisation followed an official format comprising apologies, minutes, core items and any other business. During my observations, I soon realised that LINKs' meetings were quite similar to CHCs' meetings. As Joyce recounted:

Some of the participants used to be very formal, you know having minutes, agendas and it doesn't have to be that way! But that's the way the group has decided that they wanted because that's the way they've been used to, so they are sometimes concerned that you know... 'Oh we don't have an AGM! [Annual General Meeting]' And as I say, you know, you don't have to have an AGM.

These remarks highlight a strong symbolic connection between past and present experiences. Negotiations of roles and relationships combined with an emphasis on established practices, such as the format of meetings, constructed LINKs as membership organisations that, like CHCs, were formally structured. It is very interesting to note that volunteers were quite successful in their attempts despite salaried staff continually referring back to DH guidelines and advice. Joyce, Nadine, Amy and Helen recounted several times that “when we first started we used the word member and then the DH said ‘Oh no, we can't call people members as they are participants’”. When I asked Helen to expand on this point, she explained:

I think that the idea was that participants sound more inviting, so membership might sound a bit...that's how I've understood it!...A bit exclusive...With the PPI Forums

they were members, then I think perhaps that's something the DH wants the LINK to move away from, so I think...It's participants now and not members but that probably may not have been communicated clearly enough to our participants I think.

Helen constructed officers' role as that of symbolic actors reminding volunteers that the LINK had to comply with the notion of inclusiveness and openness. Carlyle (2012) reported that, in the process of creating LINKs, policy makers and DH officers were keen to emphasise discontinuity with PPI Forums, and that the use of the term 'members' was not consistent with the principle underlying the creation of LINKs. Further, the selection of networks as organisational structures for new PPI arrangements reflected New Labour emphasis on forms of collaborative local governance as means of encouraging a plethora of actors to work in synergy (Cowell & Martin, 2003). Additionally, both health and social care were well suited to be explored through this strategy due to the multi-dimensional – and overlapping - nature of the issues involved, which would ideally be framed within a joined-up approach with other public policy sector. However, in selecting networks, whereby actors were expected to work out their roles themselves, policy-makers failed to consider the potentially powerful impact of past experiences and front-line actors' responses to deliberately permissive arrangements. Additionally, the combination of rapid changes in the PPI system and perceptions of poor legislative support for the organisations may have bewildered volunteers, who seemed to draw on past experiences, personal attributes and knowledge to negotiate the terms of participation.

Conclusion

In this chapter I have explored the social processes and meanings underlying the construction of roles and relationships within two English LINKs. I have also shown how actors' negotiations were heavily affected by a combination of factors including past experiences, personal motivations for involvement, expectations and the organisational structure of LINKs (Wharton, 1991). Salaried staff continually repeated the messages of DH guidance by reminding volunteers that anyone could

participate. However, participants actively shaped and influenced expectations as a result of the meanings that their role held for them: it was 'work', or a role of equal value to full-time paid employment, wherein individuals were expected to contribute significantly in accord with the requirements of a normal workload.

As we have seen, the English legal provisions were deliberately permissive: a practical implication of this aspect was the problem of adjustment for volunteers, who moved from a framework that was prescriptive (and more in line with the command and control ethos) to a less constraining network arrangement, where local actors shaped their own informal views about how volunteers should act. Actors' understandings and expectations formed working practices regulating the functioning of the organisation. However aspects of the old order stood in tension with the new network framework. As anticipated previously, we will in see in Chapter Seven how negotiations were contingent on the areas of work participants dealt with: in particular, roles and relationships enacted to progress the organisation were not employed in the PPI arena, where different working practices were negotiated ad-hoc, and thus created a different type of scenario.

Additionally, tensions between volunteers and officers emerged when actors sought to adjust their understandings of roles. The failure to achieve anything close to joint action (Blumer, 1969) was due to different understandings of what LINKs work entailed, and the unwillingness of volunteers to buy into the idea of the LINK as an organisation where people could participate as much or as little as they wished. My findings suggest that officers' willingness to cooperate for the common good was interpreted as intrusion and an absence of respect for volunteers as the formal source of control over the LINK. In other words, relations became strained on the basis of contrasting definitions of the situation as well as a general sense, albeit with some exceptions, that volunteers lacked trust in officers' capacity to fulfil their expectations (Sitkin & Roth, 1993). This represented a primary source of friction and was further aggravated by weak personal bonds which could have, in principle, built trust over time. We will see in the next chapter how CHCs benefitted from the presence of trust in reproducing roles and maintaining solid relationships until the reconfiguration, after which one CHC experienced relational tensions due to a lack of shared definitions of the situation. In discussing the Welsh organisational context, I

will highlight how, despite different institutional frameworks regulating involvement, LINKs and CHCs held similar views on the volunteer's role and associated expectations.

One problem with LINKs was that they lacked institutional spaces for negotiations between officers and volunteers, but this may have been exacerbated by additional factors. Firstly, Red and Greenshire LINKs did not have any formal arrangements for socialising volunteers into their role. When joining the LINK, individuals would receive an induction package, containing a brochure designed along the lines of DH documents. At a later stage, participants would receive specific training on carrying out 'enter and view' visits, which was an essential prerequisite for acquiring a Criminal Records Bureau (CRB)⁴ check and thus access NHS premises. Participants did not generally associate training with increased expertise: in fact, volunteers who had been involved in previous PPI arrangements broadly viewed such training as unnecessary as they suggested that, due to their extensive involvement in the organisation, they already possessed the requisite knowledge and skills. They constructed their roles based on the assumption that personal experience represented a sufficient source of expert knowledge: as Andy articulated "It's in my training, I suppose, really, to look objectively at situations".

The DH established and managed the website LINKs exchange, an online forum which provided volunteers and employed staff with an opportunity to discuss any issues relevant to their work, ask questions and share experiences that might improve other LINKs to advance their work⁵. In addition, research reports, guidance and general information on involvement practices were provided in the "resources" section. In a way, the website could be viewed as an institutional resource through which informants could develop understandings of the organisations and its activities. In accessing it, I recognised a few informants' names; my observational data show that only a minority of volunteers were aware of this service and reportedly they did not find the information provided by DH officials particularly useful.

⁴ The Criminal Records Bureau and the Independent Safeguarding Authority (ISA) merged to form the Disclosure and Barring Service (DBS) in May 2012.

⁵ LINKs Exchange closed on 28 March 2013.

I shall return to the issue of training in Chapter Six, where I discuss understandings of institutional and organisational factors impinging on PPI work. For now, it suffices to note that only a few volunteers and officers actually considered training to be a vital element of the organisation and a way to develop their understandings of equality and diversity issues. However the majority of participants attempted to resist these constructions through explicit reference to their perceived status built over time.

We have thus set the background for further comparisons between LINKs and CHCs in the following chapter, which will explore how Welsh front-line actors made sense of their organisational roles and acted upon those meanings to establish and sustain mutual relationships in everyday work.

CHAPTER SIX

CONSTRUCTING ROLES AND RELATIONSHIPS WITHIN CHCs

I mean the support in this office is tremendous because the relationships in the office are tremendously good, they're just so helpful, I can never ever remember on any occasion not having a nice word or nobody got impatient or angry, staff here are tremendous I have to say, and that makes a huge difference when you have a back-up staff you could rely on [...] I mean these people have been here as long as I've been here, and when you're new you need to know lots of things and I never felt anyway that I was a nuisance. If I phoned up, I never felt 'Oh God, perhaps they won't answer'. Never felt like that¹.

Introduction

As we have seen in Chapter Five, analysing how local stakeholders involved in LINKs interpreted their roles is central to understanding how organisational interactions developed against the background of the particular expectations imposed by the English statutory framework. Similarly, CHCs did not operate in an institutional void; rather officers and volunteers made practical choices within certain legal constraints that shaped the internal dynamics of the Welsh organisations. I therefore now seek to explore everyday interactions occurring within CHCs against Welsh regulations: this analysis constitutes another key discussion which helps building the argument illuminating the construction of the meanings of PPI. Throughout the chapter I also examine how far understandings of roles and relationships differed before and after reconfiguration. The new organisational structure² heavily influenced the relative stability of well-established meanings and working practices, especially within Blue LC, where divergent constructions of, and expectations about roles led to tense internal relationships.

The chapter is organised as follows. First, I will explore volunteers' backgrounds and their motivations for seeking CHC membership, arguing that the recruitment process

¹ Quotation from the interview with Stella, a volunteer from Rainbow CHC.

² See Chapter Four.

contributed to actors' understandings of their roles within the organisation, and more broadly within the local community. I will also provide a description of the backgrounds of salaried staff, highlighting the key difference between these and the backgrounds of LINKs' officers and how this shaped further internal relations along two contrasting trajectories. Additionally, I will show the positive interplay between personal bonds and trust in shaping everyday relationships (Wharton, 1991), which led both volunteers and salaried staff to describe the CHC as a 'family' or 'team'. I will also examine how and why the transition to the new organisational structure represented a significant disruption for officers and members who decided to remain involved with the new CHC; how in Blue LC new members' understandings of roles and expectations clashed with past working practices; and how these conflicts placed a strain on relationships, which in turn were instrumental in re-shaping the definition of the volunteer's role. Lastly, I will reflect on volunteers' understandings of their role as CHC members as shaped by relations with salaried staff and by the Welsh statutory framework.

Volunteers' rationales for involvement

Volunteers tended to describe their involvement as being motivated by "something to fill part of [my] time" after their retirement and to employ the skills developed in their professional careers in order to benefit the work of the CHCs. Some individuals' motivations were rooted in personal or second-hand negative experience with the NHS, and as a consequence they were prepared to contribute in order to prevent other people from experiencing the same failings in the system. Local councillors did not seem to have any real input into the recruitment process: rather, they were asked to do it, like Liam and Cindy from Blue LA told me, supposedly on the basis of their background and of their long-term involvement within their local communities. It is notable that volunteers' descriptions of their reasons for involvement are substantially similar to those recounted by LINKs' participants: within both organisations volunteers' rationale for involvement seemed to be predicated on the assumption that individuals must bracket their personal feelings

and experiences with the NHS, and demonstrate an interest “in the bigger picture” – that is, wider issues of public concern.

Additionally, quite a few members described their motivations for becoming involved as the desire “to help people, to help the patients who couldn’t help themselves”, like Carl from Blue CHC explained; Alice, another volunteer in Blue CHC, hoped to be “a voice for people who were unable to express their concerns and their opinions”, and Stella viewed her involvement in Rainbow CHC as a form of moral commitment by declaring: “we don’t mind rocking the boat for you and we will protect you; you know, we will not let you down”. They appeared to be genuinely interested in increasing people’s awareness regarding health care services, which suggests that they viewed the CHC as an advocacy organisations and members as local advocates. This is being reflected in Janice’s answer, a member in Rainbow CHC, to the questions of how the CHC could contribute to health care services:

We do monitoring, that’s one of the important things in general practice, hospital services but also again talking to the general public, making them aware of their rights. People should know their rights but most people don’t know their rights. That sounds terrible but...you know, people should know their rights but most people don’t know their rights!

The vast majority of CHCs members were retired and admitted that when they applied, they were looking for a voluntary activity that they could “keep in moderation”, as Ian from Rainbow CHC stated, in terms of time commitment. As we shall see later in the chapter, members soon learnt that the CHC generated “an awful lot of work”, and that the membership description as presented in WAG documents did not reflect the nature of their actual commitment.

Officers’ backgrounds

Prior to applying for positions in CHCs, most salaried staff worked in various roles for the NHS (ranging from administrative positions to advising on drugs poisoning in the local hospital) and only discovered the existence of CHCs when looking for new jobs. This suggests that they had some knowledge of the structure and working

practices of the NHS, which was the main body that CHCs interacted with. Additionally, at the time of fieldwork most officers had already been involved with the CHC and were highly regarded by members for their extensive experience and knowledge, which played a key role in establishing trust in the organisation's day-to-day work. For instance Joey, who was the Primary Care/Patient Involvement Officer at the start of this project, was appointed to his current role in light of his previous professional experience as a Practice Manager, which gave him the credentials required for contributing to raising members' profile. Similarly, Leanne and Simon, the COs of Blue CHC and Rainbow CHCs, had been in post for thirty-two and fifteen years respectively, which members viewed as a significant asset for the organisation. During observation of meetings it became clear that officers were also appreciated for their personal attributes, which complemented their professional knowledge, strengthened personal bonds and created feelings of respect. Joey was always friendly with members, made himself available to give them lifts, and interacted with all of them before and after meetings. He appeared to be a very confident person with knowledge of his field and the ability to make members feel involved. He was also very proud of his role across Wales and of how his position enabled Rainbow CHC – perhaps uniquely - to undertake more activities and achieve an in-depth knowledge constructed as their exclusive prerogative. Joey provided a practical example to illustrate his contribution:

The GP was saying to our members 'Oh we can only give two weeks in advance!' but well, I know, having been on that side of the desk, that in fact this computerised appointment system...they set the parameters and not the other way round! So the computer system doesn't say 'Oh we can't do that!' It is the practice that makes that decision to say 'We only open appointments two week in advance'...so I can actually say to the members 'That's incorrect, and the reason behind that is because they set the parameters and not the computer system!

Members wouldn't have any understanding so they believed what they've been told, so I can counter-argue those issues with my prior experience and knowledge. So that's my role, is to provide the members with as much information before they go on the visit with the briefing papers and all that, to making sure that before they go, they are fully armed with the questions they could ask and if they've been fobbed off,

which can happen or the practice hasn't been as open as it could be...I think probably that's a better way of putting it...It's the way for the CHC members to cut through that and actually say 'This is how this works', and what they say a little knowledge is dangerous - but as far as the practice is concerned they don't know the knowledge of CHC members; they are treating them as lay people with very limited knowledge of what is going on in their business. I am there to provide all the members with that information so they can go and actually ask challenging questions on why they are doing something.

By his own account, Joey's "prior experience and knowledge" was vital in enabling members to challenge the practice booking system and he also contributed to the shaping of their role as volunteers with accurate knowledge. He was proud of how he trained members to face a tough health care system and certain professionals, who might not be aware of the volunteers' level of competence and might be surprised to deal with "fully armed" individuals. In other words, he was committed to support members to challenge the professional dominance. Joey's view was strongly supported by volunteers and other salaried staff.

In general, employees were regarded as a great asset to the organisation. Their high level of commitment, hard work and positive attitudes represented the keystone of their successful relationship with volunteers (as will be explored further in the following section). Members were thus fully satisfied with officers' skills; similarly, NHS professionals acting in the Welsh PPI arena did not appear to question the level of knowledge of officers or the support provided to members. Although they did make comments in interviews regarding the nature of what CHCs could actually achieve and the effectiveness of their contributions, these comments did not criticise salaried staff or their role in supporting volunteers. These views starkly opposed to those of LINKs' volunteers – and a few professionals' – perceptions of salaried staff. Officers were perceived as poorly equipped workers whose lack of knowledge of specific health and social care issues, and of operational procedures, did not enable them to give adequate support to the organisations.

In the next section I will explore in greater depth the constructions of roles and relationships within CHCs and how actors interpreted and responded to the context of the Welsh legal framework.

Constructing roles and relationships

In order to set the background of how internal dynamics developed within CHCs, I will first present the legal framework that shaped members' appointment system. I will then examine how officers heavily affected the composition of CHCs as well as volunteers' understandings of their own role. Building on these aspects, I will present an idealized sketch of the volunteer's role before discussing the reconfiguration process and its impact on everyday practices of the CHCs.

The view from the top

In Wales, volunteers were appointed by LAs, local voluntary organisations and the Welsh Assembly Government (WAG)³; the latter selected members by interview. As a result, in both CHCs there was a general feeling that the appointing body would symbolically represent a guarantee for the suitability of members. In the document "Information for candidates, Community Health Council Appointment of Members" the Welsh Government and the Commissioner for Public Appointments presented an ideal profile of volunteers in a formalised description resembling a job application. Page three of this document contained a section on "guiding principles" to which future members were required to adhere: "selflessness, integrity, objectivity, accountability, openness, honesty, leadership", followed by additional descriptions of roles and a code of conduct. This information booklet could be viewed as a preliminary acceptance of roles and responsibilities and could therefore be seen as informally constituting a pre-selection process. Such prescriptive rules contrasted

³ Despite the official terminology being altered to Welsh Government (WG) in May 2011, most informants still used the older expression Welsh Assembly Government (WAG). Throughout the thesis I respected participants' use of language by remaining 'faithful' to their social worlds. However, it is informative to report that the Community Health Councils (Wales) Regulations 2004/905 (W.89) used the terminology of "National Assembly for Wales" and the CHC Regulations 2010 referred to "the Welsh Ministers" to identify one of the appointing bodies.

with the LINKs' "open door policy" as illustrated in Chapter Three. Another point of divergence from the English framework related to time commitment expected from volunteers: unlike the LINKs, wherein participants were able to determine the extent of their own involvement, the Welsh document contained a "job description" section (p.7) wherein members were expected to dedicate "three to five days a month" to the organisation.

This strong institutional framing can itself be considered as one form of construction. In their comprehensive study on the work of CHCs in the first three years of their existence Klein and Lewis (1976) explained that the bodies emerged from the need "to reconcile the emphasis on centralised planning with the currently fashionable rhetoric of local participation" (p.13). As such, in the early days CHCs volunteers were not only selected from the Regional Health Authorities, but also from voluntary organisations and LAs in the attempt to provide a form of local consumer representation. Although a theoretical discussion concerning the concept of representation is beyond the scope of the thesis, it is however important to highlight the symbolic connection between the institutional processes via which members were selected and the idea that volunteers would reflect general stakeholders' interests. As institutions, WAG and LAs represented proxies for the general population; similarly, the voluntary sector comprised a collective image of groups and people involved in providing local support. As I will outline in the next section, the requirements for actors to consider "wider issues" or "issues of general interest" might arguably reflect a perception of institutional bodies as acting in the interest of the common good of a whole area.

Despite these seemingly prescriptive regulations, actors were able to self-determine their roles to a certain degree. In the next section, I will present empirical evidence of bottom-up constructions of roles and will examine how both officers and volunteers made practical decisions that affected the scope for negotiations.

Officers: building CHCs in their own image

The formal nature of the recruitment process was a key aspect of CHCs. Informants explained to me that the membership composition was based on a selection process consisting of an interview with officials from WAG, or, alternatively, a specific recommendation of individuals who were deemed appropriate by LA and local voluntary organisations. However, Simon implemented an informal purposive pre-selection which guided the recruitment process over time. He explained to me that he, and the then chair, Abi, wanted to upgrade the role of the CHC by giving its members “some of the background about the actual monitoring and what the service was about so that they can ask much more relevant sort of questions and hold the NHS to be more accountable”. In order to accomplish this, he informally selected some people consistent with his idea of the CHC. During an interview, he recounted how such a strategy represented a shift in making sense of the volunteer’s roles:

I think over the fourteen years, you know, we did that [to make the CHC much more of a credible organisation] but of course it put a lot more responsibilities to the members; they needed to be of a much higher calibre than the members they used to be before [I became CO].

Through several local contacts, Simon managed to encourage individuals whom he considered to have the ‘right’ qualities to apply. All of these people had relatively high educational levels and were retired, and some of them also had extensive experience in the voluntary sector. Janice, for instance, stated that she was “encouraged by the retired CO - he thought I would be useful”; Ian, whom Simon also encouraged to apply, was previously involved with an English CHC and with many other voluntary activities. Pauline, who worked in a Trust for many years, recounted “I bumped into Simon and his wife Mary, who works in the Trust, and he said ‘Oh how about joining the CHC?’”. Some applicants saw volunteering as an opportunity “to use some intelligence”, like Abi put it, and their professional backgrounds to contribute to the CHC or more simply to keep themselves occupied; as Pauline stated “I think when you retire you feel that, you know, what are you going to do? You know, you can’t go out to lunch every day”. In effect, Simon’s selective inclusion found a fertile ground and shaped the composition of the CHC

into that of a body populated by motivated and competent individuals potentially able to deal with controversial issues. Abi also promoted the idea of members as individuals with a certain set of personal qualities and skills, which would transform the organisation into a near-professional body:

The one thing would be...How can one ensure the certain person that you're looking for, enthusiastic, energetic, full of ideas, prepared to be part of the team, prepared to work individually or in group? How does one ensure that you encourage that sort of person? This is a huge question! And I think what we've been doing is we've been trying through personal contacts and knowing people, approach people and say, as well as advertising and so on...But it gets very hard cause people haven't got the time so that's a big big question!

This focused perception of volunteers' role in the CHC, as reflected in Abi's description above, became so strongly embedded within working practices that it permeated organisational interactions even after the reconfiguration. The same dynamic appeared to occur within Blue CHC, albeit on a more limited scale where only a small minority of members were encouraged to apply by officers in the old organisational structure; I will consider further what bearing these dynamics had on the role construction and internal relations later in the chapter.

Simon and Abi also devised a strategy in order to manage existing volunteers by making them feel included and fully involved in the work of the organisation. In this respect, the two CHCs worked rather differently. Rainbow CHC officers developed "conversations with the purpose", a powerful motivational system that would support members to develop their skills and promote a sense of belonging in the CHC. While this tool aimed to empower individuals in their role, it could also be viewed as an attempt to strengthen "the professional front" of members, as Abi defined it in her interview. During these annual encounters, Simon and Abi negotiated professional and personal bonds with each member, asked them to review their individual and the organisation's performance, and invited them to suggest future activities. Simon and Abi also evaluated each member's contribution to the CHC and pointed out areas for improvement in line with her/his skills and interests. In doing so, they established trust on an individual level which, as I witnessed during observation, clearly

facilitated mutual interactions and aided in creating a sense of unity between officers and volunteers. “Conversations with the purpose” could also be interpreted as a means of ensuring members’ retention, which is a major source of concern for volunteer organisations (Haug & Gaskins, 2012). In these cases, Abi and the officers served as symbolic actors who attempted to develop the CHC along their preferred lines and empower members in accordance with an image of an ideal volunteer.

With very few exceptions, the selective inclusion of members of both CHCs seemed to end with the reconfiguration. However, the same logic persisted with the recruitment of co-opted members after restructuring – particularly within Rainbow CHC, wherein some experienced individuals participated in the new organisation in order to assist and guide new volunteers in their role; I will examine this point later in the chapter.

Within CHCs, officers seemed to hold a shared perspective on volunteers’ role. Lianne, expressed a common view when she explained that “volunteers should act as one body (...) they have to act as CHC members and should act accordingly”. In addition, becoming a member also meant contributing to the creation of a cooperative work environment and projecting a consistent image of the CHC. Volunteers’ intrinsic characteristics were expected to be reflected in the ability to fulfil officers’ expectations and complying with the organisations’ working practices. However, those were not easy tasks. The following quote from Ed, the CO of Hill CHC prior the reconfiguration⁴, highlights the tension between the legal construction of the CHC volunteer’s role and the perceived nature of people embedded in the community:

I think sometimes people forget why they are there, but it really is to represent...It is...In the regulations the terminology is ‘represent the interest of’...Now that is different to doing represent the community...It sounds very similar right but people who represent the community are Councillors, LA Councillors which of course we have some on our committees anyway, but representing the interest of...doesn’t always mean taking the same views as the local community [...] Often those

⁴ I first met him at a meeting before the reconfiguration; as I shall explain later, he will be appointed CO of the new Blue Sand Hill CHC in the early post-reconfiguration days.

decisions are difficult for members to make...because they come from that community.

Ed suggested that volunteers were expected to transcend their sense of belongingness to their communities in order to make decisions that would benefit their locality in the long term, even though in practice that would mean acting in opposition to local people's views, some of whom might be friends or relatives. Ed and other officers frequently used the terminology of "representing the interest of" and wording related to "representing people" interchangeably. It is informative to note that the Community Health Councils (Constitution, Membership and Procedures) (Wales) Regulations 2010/288 (W.37) described one of the functions of the CHCs as "appropriately represent[ing] the public's view on the operation of the NHS within that district" (p.23). For instance, in another part of his interview Ed stated that members "are appointed to represent the whole of their community and to work together as a team", while Dexter, the second CO of Blue Sand Hill CHC, said of members that "according to the legislation (...) they represent the local community and they get involved with discussions on planning and provision of the NHS services". Joey presented the CHC as a unity of officers and members wherein "we are to represent the public, and the views of the patients, the public and the service users". Volunteers also appeared to confuse the two functions, describing their role as being related to 'representing people in the community'. This fluid use of the terminology suggests that 'being representative' or 'representing the interests of' were actually inter-subjectively constructed through a combination of understandings of roles and pre-determined definitions of expectations. Another source of confusion for some members seemed to lie in how they defined themselves in relation to the appointing body. Some of them erroneously described themselves as "a WAG member(s)" with respect to their status as WAG-appointed members, which implied that they saw themselves as invested by the WAG with the responsibility to serve the whole community. This association suggested a powerful symbolic connotation. In fact, some volunteers explained that health care professionals' perceptions of their work were at odds with their own understanding of the role. In particular, some members were bewildered by General Practitioners (GPs) and hospital-based professionals' lack of awareness of the CHC and its function. In articulating his

conception of being a member, Eden, a volunteer in Blue CHC, explained “They [professionals] don’t seem to realise that the CHC members, although they’re a voluntary group, we have got the authority invested from the Welsh Assembly Government”.

Ed provided a practical example capturing the emotional tension that members might experience when negotiating issues of representation in making ‘difficult decisions’:

Sun is a small market town, they’ve got a community hospital which is highly thought of and well thought of by the local community, they actually had... They actually delivered live births there and the local GPs were the obstetricians, but they weren’t delivering enough to keep the skills so [...] The Royal College of obstetricians said that... to keep your skills up you should do X amounts of births per annum where they were doing way below that, so their skills weren’t...

Now they were about twenty miles from Yellowshire where there’s a major hospital with the consultant led obstetrics maternity unit... The Royal College said that unit must close but it can be a maternity unit, midwife- led unit... The CHC supported the Health Authority in that aim because one of our ... And that’s why I’m highlighting it, Silvia, in that... We didn’t... The CHC as a whole did not agree with the population of Sun who wanted to retain... They want... I mean it’s a very emotive thing, they wanted their babies to be born in Sun! The trouble is if it’s a straightforward birth that’s okay, if there’s complications they have to rush them down to Wind Town (...) Because we agreed with the health authority and our issue was... the safety of mother and baby, which is, you know, it’s paramount... But of course they’ve had a maternity unit in Sun for over ninety years and they did want to use it so it’s a very difficult balance sometimes - we were accused of not representing the views of the community but because the CHC, eventually when they become experienced, they do know more than people in the street about the health service and if the CHC had agreed to the unit staying in there, they’d have had that on their conscience if anything happened to a mum and baby.

This extract provides a telling insight on the role construction of members. Ed recalled an instance showing how the CHC actually supported the interest of the local community, which members were generally encouraged to view as the optimal

approach to healthcare in the long run. Ed dismissed local people's views as "emotive", related to attachment to an institution that seemed to foster a strong sense of community by enabling mothers to give births in their hometown. Ed suggested that members of the public attached particular meanings to the hospital in the course of past interactions with it, and by doing that they created a sense of "place attachment" (Milligan, 1998, p.2) that precluded an objective evaluation of the situation. Ordinary people were thus constructed as lacking the capacity to be objective due to focusing on emotional topics that could easily cloud the "bigger picture" and prevent them from acknowledging technical issues in the decision-making process that CHC members were able to consider. Volunteers differed from other local people by showing the abilities to draw on certain skills and knowledge to make difficult decisions about, or to challenge, technical issues. Here Ed's reasoning is similar to Joey's argument developed in the extract reported previously where he introduced the distinction between CHC members and ordinary people. Both quotes introduce the tension between the acquired qualities of volunteers and those of the constituency that they serve: I will develop further this point in Chapter Five by uncovering the processes through which the organisations constructed images of 'the public'.

In order for members to conform to such expectations, they were socialised to their role through interactions with officers and, particularly in the new Rainbow LC, experienced members had been co-opted for one year to mentor and offer their knowledge to the service of the new organisation. In both CHCs, training provision was limited to monitoring visits both in primary and secondary care, and also in relation to Hospital Patient Environment visits (HPE), which were an assessment exercise imposed by a Ministerial directive in 2003⁵. Training was generally delivered by employed staff; after the reconfiguration, some officials from WAG and

⁵ In the Foreword of the HPE Annual Report, the Director of the Board of CHC defined HPE as "a specially commissioned programme that monitors national standards of cleanliness and nutrition within the acute and community hospital settings, adheres to the standards laid down by the Welsh Assembly Government in terms of compliance with national standards and is a fundamental tool in highlighting the need for the NHS in Wales to respond to and take action on the recommendations" (p.3).

from the Board of CHCs⁶ attended a few meetings to provide general information on visits and the role of CHCs.

Before the reconfiguration, two key factors shaped a strong sense of harmony within the organisations, albeit to a much more pronounced degree in Rainbow CHC than in Blue CHC. First, volunteers felt valued as a result of their symbolic interactions with officers, who managed to create a sense of belonging to a ‘family’, like Carl declared, or ‘team’ to encourage friendly relations and mutual trust. Secondly, officers fostered personal bonds through small talk before and/or after meetings: during observations, I witnessed several instances of members cheerfully conversing with officers about their family and their spare time. Additionally, when attending CHCs meetings, members appeared to be ‘looked after’ by officers, who ensured that everyone had a lift to go back home, helped some of the elderly female members who had difficulty walking, made refreshments and checked that everyone had their papers during meetings. Additionally, salaried staff in Rainbow CHC always arrived at meeting venues at least forty-five minutes early⁷ in order to welcome members as though they were special guests. The atmosphere and the work environment may have been related to the development of internal dynamics: in other words, I never observed members aggressively disagreeing with each other in the old Rainbow CHC, and even when Stella strongly emphasised her opinion that the CHC had done a poor job of voicing its concerns regarding the proposed reconfiguration, it appeared that salaried staff and other volunteers accepted her prolonged digressions on the issue as part of her colourful personality, and in turn viewed this trait as a reflection of the determination and dedication that allowed her to contribute meaningfully to the council.

In LINKs, however, the absence of similar interpersonal bonds negatively affected working relationships, as discussed in Chapter Three. Although the host organisation officers were attentive in providing refreshments to participants and ensuring that volunteers with physical disability were comfortable seated, volunteers never suggested that officers’ personalities and individual attributes were beneficial to the

⁶The Board of CHCs was established in 2004 (see CHC Regulations 2004) as an advisory body composed of CHC members and support staff.

⁷ I often went to the meeting venues with officers, who asked me to meet them at their office about ninety minutes before the starting time of the meeting.

organisation. Conversely, within CHCs, appraisals of officers' role and personal qualities were paramount in maintaining collaborative working relationships. Volunteers regarded salaried staff as dependable sources of support whose knowledge and experience were fundamental to the organisations. This may be the reason why volunteers did not object to staff guiding some of their decisions in relation, for example, selecting NHS premises for a monitoring visit or assembling a work plan. Trust established through personal bonds appeared to legitimise staff's role and to allow them to lead on some issues without volunteers interpreting their actions as interference, as it would frequently happen within LINKs. Being made to feel supported, comfortable and appreciated seemed to remove the question of whether officers were acting in the interest of members and the whole CHC as a whole. For instance, Chris, a member of Rainbow CHC, did not seem to question Simon's decisions; instead, he made the comment "Simon used to *obviously* decide on that" with regard to some issues. Similarly, his fellow Max reported that they were "guided a little bit by Simon", and other volunteers also mentioned the role of officers in influencing volunteers' decisions.

Additionally, Rainbow CHC salaried staff made an effort to ensure that all members could interact with each other at council meetings. To do so, they used place cards to create new seating arrangements for every meeting so that volunteers would always have the opportunity to talk to different people. This plan was also adopted by the new Blue Sand Hill CHC after the reconfiguration, where all members could meet only during council meetings, i.e. approximately every six weeks. However, the infrequency of such meetings resulted in a failure to foster relationship with members from neighbouring LCs, and small exclusive sub-groups tended to form. On several occasions I noticed members rearranging their place cards in order to sit next to people they were friendly with; interestingly, these sub-groups tended to express general agreement during discussions. I will explore relational tensions and the source of conflicts that emerged in the new Blue Sand Hill CHC later in the chapter.

However, a few members in the old Blue CHC were an exception to this atmosphere of trust in officers and instead questioned their role on the basis that their contacts with the NHS weakened the organisation. In interview, Liam, stated:

They should not have an interaction with the Health Authority, you know they should be a lot more independent. My own perception, which could be wrong, is that they are perhaps again too...They're actually paid by the Welsh Assembly Government...And so I think on one hand they got...an eye on their jobs...and on the other hand they...perhaps work for the community or...they should really be only working for the CHC, they should be the administrative interface between the Health Authority and the CHC but they should not [be]...shall we say...too close [laughter] I can't think of the wording now, you know, they should be a lot more independent.

Officers were technically NHS staff because they were employed and funded by the WAG via a LHB, and this legal arrangement occasionally led them to believe that their autonomy could thus be jeopardised. In interview Ed expressed a sentiment which was not generally shared in the numerous council meetings I observed:

The strength of a CHC member is that they're independent, they're not employed by the health service and so they are able to speak freely, that if there's something they think needs to be criticised, they're allowed to criticise it. That really is the strength of the CHCs, is that they're independent so if they say something...that either the WAG doesn't like, the local health service doesn't like, they can't get at them because they're not employed by them [laughter]

Ed suggested that officers' legal status might limit the scope of their role, because, as Joey observed, the WAG "are the paymasters for the CHCs". Despite several claims regarding the independent nature of the organisations, it seemed as though officers did not feel truly autonomous from the NHS and the WAG due to the nature of funding arrangements. This seemed to challenge the belief that CHCs were completely independent, and interestingly this aspect became more apparent when officers described the role of volunteers, as in the extract above.

Another way officers tried to develop CHCs along professional lines was by requiring members to wear a CHC badge when establishing contacts with patients and members of the public, such as during monitoring visits. The role of the badge was portrayed as a positive one by the Director of the Board, who in turn instructed employers to socialise members to its use. Volunteers viewed it as emphasising the legitimacy of their role as 'WAG appointed members' as Ian explained me during a

monitoring visit that I observed. Some volunteers also wore it at meetings, even if there were no members of the public in attendance: the badge held a symbolic value that shaped a sense of belonging to CHCs.

My observational data also suggests that interactions between members and officers in meetings were facilitated by non-verbal communication as well as by verbal communication. The CO was always the point of reference for the Chair when conducting meetings, particularly in Rainbow CHC; they were in constant visual contact, and the chair would often use a glance to invite the CO to supply further information or to limit the discussion on an item due to time constraints - "we've got a long agenda today!" In doing so, the Chair may have wanted to ensure that his feelings regarding the development of the meeting were consistent with the CO's view. Also, when the Chair opened a meeting, a brief ritual usually occurred: he would look at a clock in the room then at the CO, who in turn would nod to approve his decision to start.

In an interview, Joey described the nature of interpersonal bonds within the organisation and how they contributed to foster co-operation:

As far as I'm concerned, there's a level of trust between the office staff and the members that let us work together as a team, and it is a team effort - you can't do one without the other. There are some CHCs - they don't count so well on them and there's a sort of animosity sometimes; in the situation I've been in here, we've never had that! Never had that! Yeah, we've had a member that had to be...spoken to, we had members of staff that had to be spoken to, but I can actually say that the members fully support what we do and we fully support the members. But there's also an essential thing to remember: whatever the staff do, we get the members back into do it. We don't just say 'Oh, we're doing this'; we actually ask the members first because they are the ones at the end of the day... They're the workforce, not us, and I think we have to remember that... We are there to support them, to guide and support and encourage.

His comments reflected ambivalent feelings about being part of CHCs. All officers reported that their strong sense of identification as being the CHC was shaped and strengthened through interactions with members, who also viewed them as part of the

CHC. At the same time, there was a clear acknowledgement that members were “the workforce” and that CHCs were member-led organisations; however the extent of influence on and direction of members was interpreted in a way that seemed to privilege the common good of the organisations rather than re-establishing distinction between volunteers and officers, as was often the case with LINKs.

During an interview, Ed identified the unique qualities of the organisational structure of CHCs and he argued that the nature of volunteering substantially affected the development of relationships:

If you work for a local council, if you work for a university you know there are levels of...down from vice principal or whatever they go down...Vice Chancellor they call it at the top, right? ...But then you go down to a head of department, director and that sort of thing, that's a rigid structure, but within the CHCs there's no rigidity because they're volunteers, but what you have to do is to work together as a team, to look at things in priority.

We have seen above how the WAG advert defined members' expected time commitment as between three and five days a month. However, volunteers soon learnt that much more involvement would be required, as they had various meetings to attend and documents to read. Several members commented on the large volume of papers received by officers, who regularly posted the necessary documentation for their meetings and monitoring visits. In practice, potential volunteers of working age were ruled out from participation due to the significant amount of time required. This is reflected in Danielle's decision not to reapply for a volunteer position in the new structure of Rainbow and Rural County CHC because she could not attend day meetings nor spend “so much time” on reading: she explained to me that when she first applied, she did not realise that there would be “so much to do”. As Abi recalled:

It says in the advert 'three to five days a month'. I can tell you that while I was Chair, I was in this office or doing work related to CHC at least four days a week! Sometimes five...So I think that the advert needs to be strengthened really to give a true representation of what is required.

Although as the Chair of Rainbow CHC Abi may have been busier than ordinary members, others also revealed that the amount of work required was affecting their everyday lives and that they were dedicating a few days per week – rather than per month – to the CHC. There was a general feeling that the job description did not fully outline the responsibilities of CHC members. Stella remarked “It gives you such a fault impression of what you’re expected to do” and Max described his volunteering in the CHC as a “hell of a commitment”. It is worth noting that the term ‘work’ was also used within LINKs (as shown in Chapter Five); in both cases, this word choice likely reflected an intention to portray volunteers’ role as important to their organisations.

As determined by this analysis, the role of officers in developing CHCs was vital: they also attempted to select knowledgeable salaried employees who would improve the support provided to volunteers. Employees generally committed themselves, albeit to varying degrees, to building CHCs that would more easily accomplish their intended functions and activities as set out in policy documents, and would exhibit credibility and professionalism: key attributes that were expected to affect their interaction with the NHS. Simon explained the utility of selecting members of staff in their own image:

Well, the management, you know, the management staff was all around the selection of the right people who could fit into a team, the actual nurturing of that team and the empowering of that team and the clear guidelines as to what we’ve done. So yeah, that’s what we did and I think we’ve actually achieved it so the role of a CHC once you’ve set that up was actually fairly easy.

I will further explore the relationships between CHCs and the NHS in Chapter Nine through an analysis of the construction of meanings of PPI which also builds on the discussions presented in this chapter.

The following section examines the degree to which members met officers’ expectations in their daily work.

Becoming competent members

When asked to describe their roles in general terms, volunteers gave detailed accounts of CHC activities and the organisation's aims. There appeared to be a shared sense that their roles corresponded to a pre-determined set of tasks which were prescribed by the CHC's institutional framework. The scope for negotiations regarding what to do and how to do it therefore seemed relatively narrow. However, we can imagine the understandings of volunteers' roles as a continuum, with one end representing the ideal volunteer, promoted by officers, and the other embodying a multitude of personal attributes that shaped members' roles in opposition to what salaried staff attempted to achieve.

The ideal member was one who could transcend individual experiences and interests in order to examine objectively issues of public concern. Through interactions with officers and the mentoring programme formally established for new members within Rainbow CHC, volunteers had to demonstrate the ability "to keep questions general" when voicing their concerns to professionals so that general responses – that is, responses that could be regarded as useful to a large number of people - could be generated. Later in this chapter we will see how officers, especially within Blue Sand Hill CHC, were concerned about some of the new members appointed after the reconfiguration and blamed WAG for "getting the wrong people", because they did not act in accordance with their organisation's code of conduct. I observed several instances during meetings wherein some volunteers were interrupted whilst articulating their views: this occurred particularly when their discussion of certain topics also included personal points of concern rather than "wider issues". For instance, in Blue Sand Hill CHC, Dexter usually suggested to volunteers to carry out one-to-one conversation with the professional outside the meeting room in order to pose questions and expand points of interest that reflected their needs. Generally, when a volunteer was considered unable to identify and consider broad issues, the Chair would look at the CO as if inviting him to remind members of what, and how, they were expected to do. As a result, the CO generally intervened in the debate by refocusing it on general aspects of the themes discussed.

David, an independent member of Rainbow and Rural County LHB who attended local CHC meetings prior to and after the reconfiguration, stated:

What you don't want is the message that it could be just a group of individuals having their own little individual requirements and little hobby-horses which they want to deal with, and I think this is where you have to get away from parochialism to a much more professional approach.

David suggested that in order for members' work to meet professional standards and aid the CHC in contributing to the work of the NHS, they needed to draw on their experience and knowledge of how things worked but at the same time were required to transcend their subjective perspectives to display a degree of professional neutrality.

CHC officers clearly attempted to regulate members' behaviour both within and outside their organisations by setting expectations in a formalisation of practices that aimed to socialise volunteers to use objective knowledge, although the latter was often derived from personal experiences and interests. This process might have been rooted in the belief held by both salaried staff and volunteers that the CHCs had to operate according to these principles if they were to have credibility with professionals.

Officers' and members' inter-subjective reinforcement of expectations assigned a normative value to the code of conduct: actors held negative views of members who struggled to work out the essence of their roles in practice. This partially explains why, after the reconfiguration, some Blue LC members who did not comply with codified internal practices were considered "wrong people". The danger is that rigid expectations may transform into taken-for-granted assumptions to the detriment of flexible adaptation to various circumstances.

In an interview, Sally, a volunteer in Rainbow and Rural County CHC, noted how the ability to distance oneself from one's community and achieve value neutrality was not a straightforward matter and instead entailed a great deal of reflexivity:

Something we have to be careful about as members...it's about where's the line between our own personal concerns and our role as public voices, if you like, and

whilst we may well have personal experiences that give us cause for concern, I'm not sure we should always bring those personal experiences into our CHC work. I don't think it hurts now and again if something happens and we, you know, we're really concerned about it, but I don't think our CHC work should just be a reflection of what's happening in our lives [...] Really, I do think we have to have that kind of open mind and remind ourselves why we are there. You must bear in mind you got a broader brief than just what's bothering me at any given time, you know?

Overall, expectations of volunteers were shaped by the belief that membership involved particular skills, which further endorsed an image of CHCs as professional bodies wherein tasks and responsibilities were formally regulated. In this respect, officers and experienced members created a layer of working practices regulating the work of the organisations, which over time turned into normative expectations. The following quote from Carrie, an experienced member in the old Sand CHC, described her expectations of volunteers:

So it's about being professional and observing the code of conduct; it's also about taking a full and active role in everything that we do so it isn't just about attending meetings, it's about apologising when you can't attend, it's about attending meetings, taking notes of any presentations and asking sensible questions and then taking full part in any visits.

These characteristics were originally part of an idealized conception of volunteers' role, and over time became fully integrated within actors' expectations. Such attributes reflected top-down expectations of CHC members.

Newly appointed members in Blue Sand Hill CHC (and to a very limited extent in Rainbow and Rural County CHC) were thus mainly seen as failing to comply with procedures created in the past and as such were often subject to negative judgement, which significantly impeded the development of relationships.

In the remaining sections of this chapter I will discuss how new members challenged the working practices and established expectations after the reconfiguration. First, I will explain that CHCs informants viewed the changes as an imposition which disrupted patterns of working; I will then discuss the role of officers in the transition

phase and describe the friction that emerged between new volunteers and “old heads”, as Stella ironically defined experienced members. Finally, I will delineate the new understanding of the role of members that emerged from negotiations and continual adjustment in the course of the work.

Interpreting the new top-down framework

As mentioned in Chapter One, this reorganisation was perceived as disrupting established working patterns after quite a few years of stability. Both officers and members perceived these new regulations as weakening the identity of CHCs as bodies that had achieved significant results in the past and managed to build relationships with NHS professionals through attending council meetings. These changes, along with financial cuts, were viewed as a discrepancy between the WAG’s promotion of involvement and the CHCs, and of the detrimental effects of legislative changes.

In the months preceding the 2010 reconfiguration, there was a strong sense that new CHCs would take a long time before becoming fully operational, and that new members would lack the requisite knowledge of their organisations’ history to make informed decisions. Officers also reported that they were left without “a blueprint” and that they had “to call upon a great deal of (their) experience”, as Ed recounted in an interview, to plan out what could be done and how. Similarly, members felt frustrated and disappointed believing that the Minister had disregarded their views despite their strong opposition to the proposed changes in the consultation phase. Stella and most volunteers in Rainbow CHC also believed that these changes were a “deliberate move on the part of the Minister because I don’t think she’s a great fan of CHCs”.

Members imagined new CHCs in relation to past working practices, viewing the reconfiguration as a symbolic attack on the bodies that would undermine their ability to keep the NHS accountable and retain factual independence. Max declared that “our health minister is cutting off by reducing the number of members in the CHC. She’s made it too small [an] entity in my opinion and it’s gonna be under the thumb

of the LHB”. Consequently, the majority of experienced members decided not to apply for positions in the new CHCs. The following extract from Ian captures the essence of members’ concerns:

I don't think the number's gonna be enough to do the work properly, you know...I think having been used to what Rainbow CHC have been doing, I can't see how that can be done in the new set up and I think I'd find it disappointing, frustrating. The things we used to do, it'll be useful to be able to do them now but just won't have the resources.

In both CHCs, but particularly in Rainbow CHC, experienced members seemed to romanticise the work of the organisation. Despite acknowledging that some aspects of the CHCs could have been improved in the past, such accounts were used as evidence to support their negative perceptions of the new bodies, emphasising the tension between the new structure and old members’ established expectations of how CHCs should operate. Here we can draw a comparison with English LINKs, wherein most volunteers also expressed concerns when the Coalition government issued its White Paper in July 2010 presenting the new PPI arrangements. Similarly, some of the LINKs participants who had previously been involved with PPIFs felt frustrated about the changes and how it would affect their everyday work.

By contrast, NHS professionals in both countries viewed the proposed changes positively and were confident that the local bodies could benefit from the reorganisation. Arthur and David, for instance, defined the changes as “a unique opportunity” that would improve the overall functions of the organisations and provided a new framework to create closer connections between volunteers and local areas.

The following section describes the crucial role of officers in negotiating the meaning of CHC membership in the new bodies that reflected the idealised model of the volunteer’s role established before the reconfiguration.

The role of officers in mediating change

The process of transition between the old and the new structure was critical in both CHCs. As explained previously, the reorganisation was viewed as a disruptive imposition; in practice, both CHCs spent nearly the whole summer trying to make sense of the new structure, and stated that they would not be able to start undertaking monitoring visits until at least October 2010. Officers were under pressure “to be seen doing”, as Joey put it, in light of the CHCs review occurring in 2012⁸, and they also had to address top-down requirements in terms of engaging with groups of hard-to-reach people as identified by the Minister in a meeting she held with all the Welsh CHCs representatives. A significant emphasis was also placed upon establishing connections with local voluntary organisations. Officers thus had to produce evidence of their work, but were unclear as to what constituted reliable evidence of seeking to comply with top-down instructions. At an observed executive committee meeting, for instance, Dexter pointed out that “we need to show the Minister that in fifteen months we’ve been an effective CHC so we need to translate the objectives into concrete things”.

Although several members of the old CHCs decided not to apply for positions in the new bodies, those who decided to remain involved felt responsible for assisting new members in learning their role. For instance, Stella felt strongly that:

[I] had to have some sort of input [in the new CHC]. It's not a duty but I do feel that...because I did a lot of work with the mental health side in the CHC, got very involved and I wouldn't like to see the amount of work and things we achieved rolling by the way side through lack of local knowledge by the new CHC.

There was a general sense that experienced members could facilitate the transition by ensuring that the information and knowledge produced during the earlier CHC period could be passed on to the new bodies. Rainbow CHC officers such as Joey described the function of their website and of all the documents generated as that of ensuring that the new bodies would act consistently with past decisions:

⁸ When eight new CHCs were established in April 2010, the then Minister for Health and Social Services, Edwina Hart, declared that the new bodies would be reviewed after two years. The review was actually undertaken by the Welsh Institute for Health and Social Care in May-June 2012.

We'll make sure that all the information of Rainbow and Rural County CHC is not lost and anybody knew...because as soon as we lose that, that's when things happen and you've got nothing to refer back to....So it's closing the loop! History is where you learn from you know...we've done that before so we're not doing it again!

The perceptions of the utility of “old heads” and the documents produced in the CHC before the reconfiguration relate to the concept of organisational memory as put forward by Walsh and Ungson (1991) wherein “information about decisions made and problems solved forms the core of an organisation’s memory over time” (p.62). Organisational memory is embedded in various parts of the organisations, such as insiders, websites and papers that account for past activities and choices. The roles of members and the website were therefore not only “to create an image in the public view (of) a credible CHC”, as officers explained, but also to produce sound evidence of past negotiations with the NHS and to show that the CHC could hold professionals accountable. In addition to transmitting information, “old heads” also had first-hand experience of the emotional environment in which discussions and decisions were made. The possible omissions of the complexities of interactions and negotiations from minutes or documents may also have created a need for experienced members to inform new volunteers about the CHC culture (Walsh & Ungson, 1991) in a “sharing of interpretations” (p.65).

Retaining organisational memory also aided in the construction of a reflexive narrative of CHCs history. For instance, monitoring visits reports were viewed as a means of establishing a connection between past and present and making sense of the future (Borer, 2006): through them, actors understood the meaning of their work, their achievements and the overall culture underlying the organisational approach. Like public places in Borer’s study (2010) of Fenway Park in Boston, experienced members represented the past “to people in the present” (p.210).

This broad context framed officers’ strategies to ensure that some old members stayed and to establish the ‘right’ type of new volunteer in key positions within the new CHCs. To a limited extent, Blue Sand Hill officers attempted to replicate an approach similar to the purposive selection of members enacted in Rainbow CHC. In

an interview Ray, an experienced member that continued his involvement in the new Blue Sand Hill CHC, shed light on the process of his reappointment:

A lot of people have left who should be still on it, and they've gone because they haven't applied to become members, again, I mean what was the point of that? You know, Ed knew what we were doing, how good we were, if he wanted us or not and that's what happened with me. I refused to fill in the forms properly so the WAG didn't ask me for an interview...so Ed and I had a conversation. He said "But I need you! Is there anything you belong to that is attached to you know a voluntary organisation?" And I said yes, nothing to do with health, it's the local history society, and he said fine, and within an hour I had a call from X saying 'Will you represent us on the CHC?' And I said yes, okay, so that's how I got back to the CHC and I just threw my toys out of the pram, you know when I had the call - I mean they were asking me things that Ed knew, I mean he was better placed to make a decision on whether I was right or not than they [WAG officers] were.

Ray strongly contested the WAG's approach to the appointment of volunteers; he and Ed managed to resist the legal construction of membership through local negotiations. Generally, members displayed hostility to the idea that the WAG rather than officers ultimately selected members of the CHC, arguing that salaried staff had the experience and the knowledge needed to determine which applicants could be valuable members, and that the WAG's institutional position and distance from local operations were not conducive to making informed decisions. WAG officers were thus blamed for the difficulties that employees (and members) experienced in managing new volunteers. Ray stated that such a top-down approach conflicted with the drive to select the 'right people' who could ensure continuity and consistency of understandings, and would sustain established courses of action. Similarly, Carrie contended that:

Some people had applied and didn't get through although they would have been more than suited to do the job because they were doing it for the right reason. Some were put off by the process anyway, and didn't even apply, and a lot of the people that did apply had single agenda issues so that has made it difficult in some areas.

The second CO of the new Blue Sand Hill CHC, Dexter, who acted as CO of Rainbow and Rural County CHC for a few months immediately after the reconfiguration, attempted to create closer connections with members. In October 2010, he delivered an opening speech at the first meeting he officially attended in his capacity as CO. The following extract from the field notes reconstructs the portions of the meeting where he presented his strategy to the general membership:

Dexter said that there will be a Standard and Executive sub-committee of the Executive Committee - 'I know you're all volunteers but in the course of the term you'll meet a certain amount of work, visiting and some other things as well...The sub-committee will monitor the progress of members with a conversation with each of them to see how we can work well together. If you can't get to us, I'll come to you, I'll come to see you...In terms of members, I'll make sure we look after you in that sense'.

Probably following his brief experience as CO, Dexter decided to adopt his version of “conversation with the purpose”. In doing so, he aimed to foster interactions that would form a sense of membership in an organisation which was largely viewed as “having problems with members”. In addition, he also acknowledged that some of the older volunteers who lived in small villages and had restricted mobility might struggle to establish regular contacts with officers. In describing the workplaces of the organisations in Chapter Two, I highlighted the difficulties that I also experienced to reach Blue CHC offices.

Most of the encouragement for new members to adjust their behaviour to fit an ideal model came from officers. For instance, both CHCs were involved in public consultations about proposed changes to local health care services during autumn 2010. The CHCs were responsible for negotiating a considered approach to such changes through a formalised vote of the Executive Committee, which would either agree or refuse to support LHBs' plans. Members were expected to attend public meetings arranged within their communities in order to listen to the local people's concerns regarding the issues discussed, which would in turn be considered in the decision-making process.

Joey explained that in Rainbow and Rural County CHC, he expected all members to express their views regarding the relocation of several services from some relatively central sites to peripheral areas within the Local Authorities boundaries. However, two new members, Audrey and Sam, argued that they had no first-hand experience with the services included in the consultation and hence did not wish to be involved in that particular discussion. Joey thus asked them to attend individual meetings where he laid out the reasons why they needed to contribute to the work of the CHC by actively participating in the debate, regardless of whether they had actually experienced the service under scrutiny. Joey's construction of membership was similar to that expressed in "Beyond the Boundaries. Citizen-centred Local Services for Wales" (WAG, 2006), also known as the Beecham Review Report, which argued that "the citizen model recognises that the public [...] have responsibilities to be concerned about the services available to everyone else" (p.6). WAG's statements about the citizen model and principles for involvement may therefore be more embedded in citizen-engagement organisations than initially apparent.

The next section explores how new volunteers and their new interpretations affected the early days of the reconfigured CHCs. Particular attention will be devoted to Blue LC, where I observed significant tensions in negotiating understandings of the volunteer's roles and, consequently, in interactions.

Conflict and factions

As illustrated above, the reconfiguration challenged well-established understandings of members' role, which covered a pre-defined set of topics that CHCs would normally investigate and scrutinise (such as delivery of services, environmental conditions of NHS premises, and LHB operational plans). Officers and old members displayed some difficulties in dealing with new volunteers, particularly within Blue Sand Hill CHC.

Although some members had been extensively involved with other voluntary sector organisations, officers strongly believed that the CHC was a unique body, with equally unique practices. As examined previously, volunteers were expected to

distance themselves from personal interests and circumstances in order to focus on the broad context of the issues discussed. Additionally, new members struggled to understand that, when attending external meetings, the “CHC hat” represented the master status (Hughes, 1945) on which their work identity would be based. Interactional tensions thus became visible due to diverse interpretations of roles and, perhaps, some personal traits that did not facilitate communication. As a result, new volunteers created a “difficult” situation because they actively attempted to resist and reformulate the constructions of roles presented by officers and old volunteers. This conflict generated internal factions, with one group of new volunteers seeming to stand in opposition to the rest of the organisation. These definitional processes substantiated Thomas and Thomas’ famous pronouncement (Thomas and Thomas, 1931, cited in Smith, 1999, p.62) – “if men define situations are real, they are real in their consequences”.

By defining some members as “difficult”, actors increased the symbolic gap between new volunteers’ and other volunteers, which was detrimental to the construction of a sense of belongingness within CHCs, as those members perceived as problematic tended to distance themselves progressively from their peers. This was apparent not only in the infrequent interactions between the council as a whole and the group consisting of new members Rose, Anne, Gabriel and Amber, but also in their physical occupations and uses of space within meetings, which consistently mirrored the growing social distance between the factions. Nevertheless, officers attempted to promote sociability amongst members, especially those of different LCs, who would meet every six weeks for full council meetings. Similar to procedures used in Rainbow and Rural County CHC, officers used place cards to vary seating arrangements in order to facilitate conversation and develop the pre-reconfiguration sense of the CHC as a “team” or “family”. Despite these measures, however, I observed some of the new volunteers moving to a seat next to fellow volunteers with whom they had friendly relationships, which increased the social divide even further.

As discussed previously, Blue LC officers and experienced members suggested that the selection of “difficult” or “wrong” volunteers was the result of an ineffective recruitment process implemented by WAG officers. In an interview, Esther, who was

PPE officer in Blue Sand Hill CHC, discussed how these individuals affected established working practices:

Getting members to understand what the CHC is all about, I feel there's too many issues or self-issues with members and I don't know, that's come through the WAG but they've got people sitting on the CHC now who're only concerned with their own issue. We never had that in the Blue CHC. There was a bigger issue that everyone was concerned about and I do think that that has taken a lot of our time, trying to get people to realise that you're here to serve the whole of the area, not just your little community you know, your...whatever the word is, sort of.....group, isn't it, you know?

Esther saw new members as creating a new situation that “we never had”, since in the past nobody struggled “to understand what the CHC is all about”. New volunteers also appeared resistant to being socialised. From a symbolic interactionist perspective, a *definition of the situation* is a process wherein individuals negotiate with the intent of establishing a shared understanding of context, roles and expectations; this, in turn, allows actors to advance their work. However, when actors struggle to arrive at a shared definition of the situation, interactions can become very tense. The second Blue LC meeting represents a powerful instance of conflicting roles' construction and how this led to strained internal relations. I reconstructed interactions and attempts of negotiations in my field notes:

Rose argued “I wouldn't like to think that this new CHC will be just a continuation of what has been done previously”. Eden, and experienced volunteer who was also the chair of the new Blue LC, mentioned the legacy statement as a guide for the CHC and Rose commented, “I thought it was about Blue LC deciding new problems. Her tone was a bit aggressive. Cindy, a local councillor, came in “We've identified these problems in the past”, and Ed made clear that “When everybody will be trained, you'll be ready to start your own activities and everything”.

Rose looked terribly annoyed and said in a loud tone of voice “We don't need further training, I mean, we're already all experienced members!” Anne, another new member, added “We've got only July and August before starting the HPE (Hospital Patient Experience), what do we do in the middle?” and Eden talked about his

previous experience when he first started as a member – “Reading newspapers and keeping an eye on public issues”. Rose remarked “There are a lot of problems out there, I mean, what’s the mechanism? Who do I pass them through?” and Ed observed “We still have to have our own programme even though we’re representative of the community we serve”.

Rose looked nervous and angry now. She asked “Is the legacy statement our programme?” Ed: “It’s the programme of Blue Sand Hill CHC! I understand the frustration but...” and Rose: “It’s always about monitoring visits! If it’s supposed to be new, why do we have to stick to the old programme?” Ed was struggling to answer, and the confrontational tone of volunteers certainly wasn’t helping. He said “There’s been monumental changes; we’re frustrated as well. There haven’t been any changes as far as you’re concerned, though. What they told us is: train members and then you can start the visiting!” Eden argued “Visiting is just one part, the other one is to bring problems to these meetings”. Amber, a new member, came in “You’ve been to Blue Hospital, for instance, as you said earlier, so how can we know when this is happening? How was it decided?” and Ed explained that it was only a follow-up visit. Rose snorted repeatedly. Amber asked “How long does this training take?” and Ed said it would take one day. Norma, the chair of Blue Sand Hill CHC, who was also a member of the old Hill CHC, explained “HPE is on an all-Wales basis, the external visits we’re asked to do” and Rose “I’d like to know exactly the route to follow. When are we going out to talk to patients? With the HPE?” and Ed replied “No no! You talk to patients when there are monitoring visits!”

Gabriel, another new member, also came in: “I was at a Disability Forum yesterday and they know that I’m sitting here as well, as we wanted to involve the CHC but the CHC isn’t working; we’re not doing anything!”. Anne argued “We need to raise awareness! Can we go to represent the CHC or do we need to be trained? It was raised in the last meeting and what has been done?” Her tone here was slightly sarcastic. Ed explained “Further on the agenda there’s a PPI committee. I can do a press release but it’s better if you have an input in it. I can’t do things on my own! I had no guidance to guide the CHC, I know it’s frustrating but...”

Anne observed, "We're all full of enthusiasm and our expertise...In order to get there, we need to do this again [the training]. It's a lengthy process! What can we do now?" Amber replied sarcastically "Reading the newspapers, for God's sake!" but she semi-whispered it to Gabriel and Rose who were sitting next to her. Then she rolled her eyes and alternatively looked at Gabriel and Rose as if she was seeking out a visual sign of tacit approval. Esther and Lianne didn't say anything and they repeatedly shook their heads whilst observing the whole discussion.

This extract is particularly revealing. Rose, Anne, Gabriel and Amber were all new members whose views clearly differed from and, to a certain extent, directly contrasted with established expectations of volunteers. There was a general sense that the legacy statement⁹, which symbolically represented the old CHC, could prevent the organisation from identifying a wider variety of local issues and that the methods employed – such as “reading the newspapers” – were deemed ineffective. They also wanted to establish connections and attend other organisations’ meetings on the basis of their belonging to multiple groups and therefore saw formal training as an unnecessary hindrance to the work of CHCs. Ed and a few experienced volunteers attempted to frame the current local situation in a larger context defined by uncertainties and adjustments which were structured according to legal requirements imposed by higher institution. This conflict parallels the experience of some LINKs’ participants, who also disagreed with their organisation’s view of training as a means of legitimising volunteers’ right to undertake ‘enter and view’ visits. In both bodies, a group of volunteers viewed training as an unnecessary layer of bureaucracy that prevented actors from actually doing the work and fully participating. Officers were ‘squeezed’ between volunteers’ understandings and the statutory framework, which did not acknowledge individuals’ subjective experiences as a foundation on which roles could be built.

Members’ personal commitments and physical disabilities seemed to clash with officers’ managerial aspirations for Blue Sand Hill CHC. Dexter decided that Tuesdays would be “CHC days” when they would hold all meetings during day

⁹ The legacy statement was a document produced by both CHCs towards the end of the old organisational structure in which they highlighted key local issues and aspects that the new CHCs might be willing to monitor. The document can also be seen as another component of the organisational memory of the bodies.

times: his justification for this focused on the need “to standardise the work across the CHC” and also to facilitate the administrative functions of office managers. However, some members expressed disagreement, such as one member who voiced his concern at a council meeting after Norma expressed her disappointment about a poorly attended training day. The member argued that the meetings “would be better in the evening or at the weekend, and rather than blaming people the CHC should organise the meetings at a convenient time!” Despite similar comments received on several other occasions, officers did not modify the schedule of meetings. Additionally, some new volunteers showed interests in disabilities or disability-related topics as a result of their own physical impairment or first-hand experiences as carers. Prior to the reorganisation, the absence of members with ‘visible’ physical disabilities meant that disability-related needs were not considered in the daily work of the organisations; for instance, I never observed discussions about arranging meetings in accessible buildings or considering disability-related issues as topics for scrutiny. In both CHCs, salaried staff made efforts to limit expenses and therefore tried to maintain deals with the NHS and LA that allowed them to use meeting rooms for free. These working practices were strongly challenged when Gabriel, a wheelchair user, and others close to disabled people became members and asked officers to consider accessibility issues. Their request did not solely refer to contingent needs; rather, it symbolically highlighted a need for attention to disability in general and more broadly to equality and diversity issues. However, as a result Gabriel was defined as a “wrong” type of member with a “personal agenda”, and his interests in accessibility were construed, in Ray’s words, as “pushing on one point”:

The biggest challenge is always getting people and the bigger challenge is getting the right people and I think that in many cases they [the WAG] got the wrong people, they’ve just taken anybody with a problem. I mean we’ve got a situation in Blue LC where we’ve got three people who are wheel-chair users – well, it is very important that those people are represented but not to the point where you’ve got three of them and all that happens then is you’re pushing for one on one point. I mean people in wheel-chairs get heart attacks, chest complaints and Alzheimer like everyone else and the main issue is how do you treat heart complaints, rhino complaints etc etc? Yes, these people must have access but I mean really that’s all they wanna talk

about, the people like Gabriel in Blue LC and the other people in that situation - that's all they're concerned about and that's the one thing that you mustn't do is focus on one issue, you've got to think of the whole, the whole service in the whole area, which is a big beef.

The CHC represented “the public’s view” (CHC Regulations 2010) rather than the composition of its local area, even though, as discussed previously, the boundaries between these two concepts were blurred in talk. Ray embodied the established ability to consider only issues of public interest: his assumption seemed to be that the vast majority of people in the community needed effective stroke units rather than buildings with disability access. He attempted to establish clear definitional boundaries for the CHC by arguing that its remit was purely concerned with health services, and that accessibility and equality issues were not necessarily NHS concerns. These examples suggest that a very narrow definition of what did and did not constitute health issues was in operation in these organisations.

Following Ray’s argument, due to a perceived minority of disabled people in the area compared to the amount of people in need of services that fell into the category of health services, accessibility was not seen as fundamental to the work of the CHC.

Therefore, the CHC was responsible for scrutinising services but not for ensuring that everyone could actually access those services in the first place. When Gabriel asked to arrange a meeting in an accessible venue, Esther did select a fully accessible building in Hill town, but emphasised several times that the venue was very expensive and that the cost would significantly affect the tight budget of the CHC. On the day of the meeting, Gabriel was unable to attend and sent his apologies. Esther observed bitterly “he asks for this and then he doesn’t even turn up!” Another member echoed her comment, and Ed expressed his agreement with Esther by repeatedly shaking his head. Esther’s remark may be viewed as a form of moral judgement, which was easily dispensed to “difficult” or “wrong” members. Esther also mentioned some volunteers’ lack of respect for a formal code of conduct, such as sending apologies when unable to attend a meeting, and other officers reported that there was a poor commitment to contributing to all CHC tasks, as evidenced by some volunteers’ last-minute withdrawals from attending monitoring visits. Although

these withdrawals may have had a range of motivations, officers such as Esther assumed that new members “just don’t like visits”. As noted above when discussing constructions of members’ roles, formal procedures played a key role in CHCs’ activities and to a certain extent in LINKs, whose participants also attempted to standardise the work of the organisations through formal working practices. The latter were so entrenched within this CHC that they not only heavily limited the scope for negotiating roles, but also affected the selection of topics that were perceived as appropriate for the organisation.

Consequently, in Blue LC there was a clear demarcation between experienced and new members, and the latter progressively distanced themselves not only from the rest of the local committee, but also from the rest of the council membership as a whole. It was difficult at times to maintain order, and the group consisting of Gabriel, Rose, Anne and Amber was quite confrontational in meetings that I observed. In addition to verbalising their disagreement, they also expressed their view through non-verbal behaviour such as loud puffing and staring at individuals to draw attention to them.

Although officers never verbally articulated their frustrations and the difficulties in dealing with members in meetings, their non-verbal language indicated how they felt (rolling of eyes, puffing, shaking of head).

The examples provided in this section offer an insight into the reasons why some new members’ expectations clashed with old volunteers’ and officers’ perspectives on the ideal model of CHC membership. In the wake of the reconfiguration, a new understanding of the role of volunteers emerged, which is outlined in the following section.

Redefining the role of volunteers

After the reconfiguration new members introduced a variety of locally-focused needs and perspectives to the CHC, which were seen as opposing established understandings of organisational tasks and working practices. For instance, Gabriel wanted the CHC to adopt a Disability Policy and wanted to be actively involved in

the process. Although the Board of CHCs was formally “committed to its Disability Equality Scheme” (Board of CHCs, Annual Report 2009-2010, p. 9), in practice it was unclear how both the Board of CHCs and CHCs would address such a document as well as the Welsh Assembly Government’s Single Equality Scheme (2009-2012). Further, the Board of CHCs Annual Report 2009-2010 (p. 9) reported the presence of a small budget allocated to cover expenses for certain services that would increase the degree to which members could participate in CHCs (such as text to speech computer packages and childcare). However, in reality, officers always claimed that they did not have any additional resources to support, for example, the costs of translation facilities or accessible venues. This attitude may have been partially rooted in the selection of terms. For instance, the Board of CHCs Report 2009-2010 emphasised the need to undertake “core CHC duties” (p.9), whereas ensuring members’ participation and contributions from patients’ and members of the public’s seemed to be a secondary concerns. ‘Doing the work’, such as monitoring visits and “keep(ing) the NHS” in check, like Abi reported, was also a top priority. New members were viewed as over-emphasising concerns that officers did not deem equal in priority to the core duties that they had to undertake.

Conclusion

The chapter examined how volunteers and officers constructed their roles and how such understandings crucially shaped internal dynamics and interactions. It also explored officers’ backgrounds and volunteers’ motivations for becoming involved, and demonstrated the striking contrast between the former and LINKs’ salaried staff. The prescriptive nature of the Welsh statutory framework compared to English legal provisions seemed to restrict possibilities for shaping the system; however, in practice, CHC officers and members made sense of organisational roles and devised strategies that would promote the recruitment of the ‘right’ individual via methods similar to those used by LINK volunteers and some professionals, albeit in more pronounced ways. Through building CHCs in their own image, officers developed formalised meanings that acted as normative rules governing volunteers’ roles. In contrast to Martin and Finn (2011), who discussed the lack of the user’s role in pilot

cancer-genetics services and its implications for the work of staff, my study demonstrates that CHCs members' roles were neatly constructed and eventually internalised in accordance with officers' expectations and that, despite some exceptions after the reconfiguration, officers' and volunteers' views did not allow for controversial understandings of roles. Conversely, within LINKs, the host organisation employees and participants particularly struggled to negotiate mutual understandings of roles in relation to the loosely defined facilitative task that the DH assigned to the host organisation. Here the contentious issue was related more pragmatically to a strict division of labour, which heavily affected internal negotiations. Like CHC members, however, LINK participants were very clear on the set of expectations that constituted their roles, and as such used these to assess other volunteers' contribution.

My findings also contradict Learmonth, Martin and Warwick (2008) when they

suggest that it is simply unrealistic to expect individuals in unpaid and entirely voluntary positions to devote substantial amounts of time and effort to a lay role, particularly when they become aware that their work is at high risk of marginalisation and dismissal (p.113)

CHCs members dedicated a considerable amount of time to their organisations, sometimes to the detriment of their personal lives. Similarly, regular LINK participants were seriously involved to the point where some of them struggled to enjoy their volunteering and lamented the lack of committed volunteers who could alleviate their workloads. For instance, Sheila eventually resigned from her position as Chair of a working group because 'it was just too much' (see Chapter Five). In both bodies, volunteers were genuinely keen to improve the local health services by offering their contribution regardless of the expected outcome of their involvement.

The need to develop objective knowledge and to pay attention to 'wider issues' of public concern may be related to the fact that the health care system is based on commissioning services grouped into broad categories. Officers and volunteers may thus place strong emphasis on definitions of roles and remits as they are expected to conform to the nature of professionals' needs. This may suggest that citizen-engagement organisations need to align their working practices and underlying

assumptions with those of NHS bodies' at a fundamental level; as Learmonth et al. (2008) suggest, "perhaps, performance management also tends to create a context in which the public voice is expected to focus on established agendas concerning health-care priorities and strategies" (p.113).

Another main point of discussion relates to the expectations placed upon volunteers to manage multiple roles, which I also observed within LINKs. In the example I reported about the community hospital, Ed explained that emotive issues related to their immediate communities could cloud volunteers' ability to see the 'bigger picture'. Carrie also argued, "if you take out the emotions, you look at it...not in a cold way but you take account of...other issues such as clinical issues and the financial issues and in terms of health and safety as well". This attribute required members to be reflexive and acknowledge the personal impact of the topics discussed. Volunteers were expected to remove emotions and personal interests from their activities in order to aid the CHC in displaying a 'professional front' and officers strongly conveyed the belief that showing emotional attachment whilst making decisions or discussing a topic was a reflection of a personal approach to public issues. Similarly, LINK volunteers claimed that interests in 'single issues' could be detrimental to considering the larger context in which services were designed and delivered. The ability to 'take out the emotions' is reminiscent of Hochschild's feeling rules (1979, p.551), which provide symbolic instructions on how individuals are expected to behave in certain circumstances. Volunteers were expected to do some emotional labour (Hoschild, 1979) through which they sought to render visible the key features that differentiated them from ordinary members of the public. Members of the public were generally deemed unable to follow volunteers' principles and act accordingly, as I shall discuss in the next chapter. This view seems to imply that informants, in both organisations, were required to subscribe to an established pattern of action that reflected an idealised conception of the volunteer's role and professionals' expectations of what the organisations could and should contribute. The social context framing subjects' negotiations of meanings was thus a key component in my analysis.

New volunteers in Blue LC sought to resist established understandings of roles and move beyond the rigidity of such boundaries. However, their attempts were

tortuous and negotiations were strained. A few months after completing my fieldwork, I noticed that Gabriel, Rose, Anne and Amber were no longer listed on the Blue Sand Hill CHC website as Blue LC membership. By contrast, in the new Rainbow LC and in the council as a whole, I never observed similar tensions with new volunteers; here, it was experienced members who struggled to understand the new organisational structure. Stella and Shirley, who were co-opted in the new CHC, felt that the EC excluded the council from full participation, and expressed a desire to return to the 'old days', when decisions were made jointly by the CHC rather than by a very small group of members (i.e. the Executive Committee). However, officers promptly renegotiated Stella's and Shirley's roles by granting them the responsibility for leading monitoring visits and reviewing a policy document to create a digest for the whole membership. By assigning them some relevant tasks and implicitly showing that their contribution was still appreciated, officers reformulated members' feelings of symbolic exclusion into a strong sense of belongingness.

If the English legislation wherein 'Everyone is welcome' emphasised an inclusive construction of participants, the Welsh legislation conveyed a less inclusive message in the detailed job description that I discussed previously, in which an idealised profile clearly emerged from the list of expected personal attributes. However, although the statutory frameworks in these respective countries seemed to take distinctly the characteristics required to become a volunteer, in practice both organisations negotiated similar versions of volunteer roles.

Building on these arguments regarding the constructions of roles and relationships, in the next chapter I discuss how LINKs and CHCs constructed certain images of 'the public' as one of the key bodies they were established to serve. In particular, I will show how volunteers drew upon their positive understandings of the organisational insider to formulate negative perspectives of 'the public'.

CHAPTER SEVEN

CONSTRUCTIONS OF THE PUBLIC

People won't come to consultation meetings unless they've got something to say, people won't come to the consultation meetings unless they really are affected as they think by the services being withdrawn, and as a consequence the majority of people will just...not do anything about it. You can't assume that they're all in favour of the closure [of a hospital] you can't assume that, but at the same time if people have the need to say something, they'll come to meetings. So when you go to meetings and there are only two or three people, you can see that only two or three people got any concern¹.

Introduction

This chapter examines the social processes via which LINKs and CHCs arrived at particular conceptions of 'the public' in the course of interactions and the everyday work. The analysis reveals that volunteers' constructions of 'the public' were closely interrelated to, and constituted an integral part of, their understandings of organisational roles as presented in Chapter Three and Four. In addition, images of 'the public' informed the discussion on meanings and enactments of PPI explored in Chapter Eight and Nine.

CHCs and LINKs were established *inter alia* to gather information from the local population on the nature of health and social care services in order to contribute to improving the delivery of those services. Policy makers intended the bodies to forge meaningful relationships with patients and the public, although these two groups may be viewed as addressing a monolithic constituency of common interests, which at the very least ignore a conceptual distinction of needs and experiences that has already been addressed by various scholars (Lehoux et al., 2012; Martin, 2008, 2012; Tritter, 2009). Tritter (2009) argued that "individual patient decision-making" (p.278) dominate the policy focus of PPI. On the other hand, previous examinations (Barnes,

¹ Quotation from interview with Dexter, CO of Rainbow and Rural County CHC first and then of Blue Sand Hill CHC.

Newman, Knops, & Sullivan, 2003; Litva et al., 2002) have discussed the socially constructed nature of 'the public' in involvement activities.

My analysis revealed a matrix of meanings and negotiations through which CHCs and LINKs made sense of the public that they were apparently established to serve. The routine activities appeared to draw CHCs and LINKs towards patients. Thus CHCs members and officers were particularly keen to undertake monitoring visits on NHS premises, which represented a key task prescribed by the statutory framework. Before the restructuring, Rainbow CHC developed a few sub-groups to investigate specific issues related to primary and secondary care. At the same time, two distinct groups of volunteers were responsible for monitoring the local provision of cancer services and mental health services. Similarly 'enter and view' visits represented a valued activity for several LINK volunteers. Most of both LINKs' working groups aimed to look at patients' and service users' experiences and their unmet needs in relation to different areas of the health and social care systems.

However, despite a tendency to consider patients as the broad target group for most CHCs and LINKs activities, 'the public' was another entity mentioned within WAG, DH and NHS documents. 'The public' made up an "imagined community" (Salazar & Orobitg, 2011; see also: Anderson, 1983) from which LINKs were to gather issues and concerns about health and social care services (DH, 2007, 2008, 2009), and whose views CHCs were tasked with representing (CHC Regulations 2010). The idea of 'the public' was used frequently by informants (particularly volunteers and CHC officers), both in interviews and in observed meetings, to supplement insiders' constructions of roles.

Exploring the meanings that underpin images of 'the public' is thus a necessary step in illuminating the social context in which PPI policies are planned and implemented. To do so, I will highlight the role of imagination as a key component of actors' social interactions and negotiations of meanings, generating my discussion from what Anderson (1983) terms "imagined communities". I will also consider how salaried staff and volunteers drew on imagination to shape the public and its relations with the bodies; informants' accounts and observed reactions revealed an epistemic contrast between volunteers' positive reasons and members of the public's negative

circumstances that motivated both groups to participate. I will then illustrate some pragmatic consequences of the imaginative process by discussing how the public was embodied through meetings and made visible through public encounters. Further, I will argue that the public served as a reference point for volunteers constructing their own roles, so that the implicit contrast between volunteers and 'the public' informed the reflexive process via which they constituted their identities as LINKs and CHC insiders. I will critically review the strategies devised by actors to create 'the public', and will show how understandings of roles and practical decisions to advance the work of LINKs and CHCs reinforced a 'belongingness divide' between volunteers and ordinary members of 'the public'. In conclusion, I will also make some observations as to how LINKs and CHCs might question the representativeness of some marginal groups as they carry out the work.

Imagining the public

Imagination is a topic that sociology has failed to recognise in its analysis of social relations (Adams, 2004) as well as a practice of collective acts (Borer, 2010). Like Borer (2010), I consider imagination to be an enlightening process, and as such it is a useful tool through which we can explore the rationales underlying actors' constructions of the public.

Within CHCs and LINKs, imagination functioned as an asset to bring the public into being and a resource to construct images holding, as we shall see, a symbolic power. In Anderson's terms, 'the public' is foremost an imagined community, as "all communities larger than primordial villages of face-to-face contact (and perhaps even these) are imagined" (1983, p.49). Volunteers' strong sense of belongingness to LINKs and CHCs was shaped by their active involvement: the organisations became proxies of an imagined community of individuals particularly devoted to civic engagement. In contrast, 'the public' was a distinct entity created by symbolic boundaries rooted in volunteers' self-understandings of roles. In addition, there was a common tendency among volunteers to associate automatically the public with a lack of participation: the former often expressed disillusionment regarding what they could realistically devise to tackle the present situation.

'Involvement' in the NHS has been on the political agenda since the establishment of CHCs in England and Wales in 1974 (see Chapter One), and has occupied a prominent position in political discourse since Labour Party's return to power in 1997. Also, the Local Government and Public Involvement in Health Act 2007 placed a legal duty on the NHS to involve patients and the public although some commentators argue that this duty has been weakened compared to the wording used in the NHS Act 2001 (Mullen et al., 2011). Furthermore, it is instructive to highlight the symbolic role of the NHS, an institution created in the post-war era which is often used to represent a distinctive trait of Britishness, to the point where the NHS was celebrated in the London 2012 Olympics Games opening ceremony. Prime Minister Winston Churchill's memorable quote regarding "cradle to grave"² care, suggests that we will all need NHS services at some point of our lives. As the NHS is a publicly-funded institution, citizens are expected to respect it, love it and take good care of it. As Andy asserted, "if you don't look after your health service, you will lose it!" The symbolic meanings attached to the NHS may create an obligation, and perhaps a pressure, for individuals to 'return the favour' by looking after the NHS, just as it looks after them when they need it. Becoming actively involved in LINKs or CHCs may be one way to meet this obligation.

Accordingly, volunteers offered positive reasons to explain their participation and contribution towards the NHS. Joey corroborated this interpretation in an interview:

I always trust myself as being a flag-bearer [and] watchdog of the NHS while I am alive. When I am dead it is somebody else's job and hopefully I'll have a good service in that process. For young people, they're gonna be the future doctors, dentists, opticians, pharmacists, they'll be the future working public within the NHS. They'll be the ones I will ask when I get old which isn't far away now...I want to be able to know, when I get old, that I can go to somebody to ask their help if I need help, and I want them to look after me and treat me with respect and there's one way of doing that: by getting involved, by knowing there's somebody watching over them and to make sure that they are doing it right, making sure that's happening.

² The phrase was used by Prime Minister Winston Churchill in the speech "A Four Year Plan for England" broadcast from London by the BBC on March, 21, 1943.

Joey's statement parallels the reasoning displayed in Borer's (2010) study concerning a neighbourhood's urban redevelopment project. Joey rooted his argument for commitment in a conception of participation that extends beyond the necessity to address present needs and issues; the decision to participate was based on his imagined future health needs. This extract exemplifies the act of imagination as a means through which actors made sense of their present roles; there was a common perception of personal commitment as a tool to improve services for themselves and others users in the future.

Overall, involvement in the community as a whole and in the NHS in particular was pursued as a highly regarded activity. As illustrated in Chapter Five and Six, volunteers' reasons for becoming involved were positively related to the expected results of participation as a means of working towards the improvement of local health services. However, these beliefs appeared to lead to negative judgements about people who did not participate and a failure to recognise the reasons for alternative choices.

Volunteers' self-understandings of their role were positioned on a continuum of participation (as argued in Chapters Five and Six): while they saw themselves as being located near the top end of the continuum, the public was imagined to occupy "the lower end of the scale", as Luke put it. The public was constructed as mainly uninterested, apathetic, lacking civic commitment, altruism, responsibility towards a collective service and, implicitly, lacking any sense of ownership of health and social care services in the local community. The public's physical absence at meetings was mainly translated into an assumed lack of interest in participation and the issues discussed. These beliefs were rooted in tacit knowledge: no volunteers ever provided any firm evidence to support such claims. Imagination was used to infer what 'the public' thought, and to make assumptions regarding 'the public's' preferences.

This interpretation failed to consider fully the multiple real-world pressures and circumstances that might limit people's ability to get involved. Most participants did not consider issues related to the working practices of the organisations or the nature of the top-down support provided by the overseeing government departments when they dismissed 'the public' as disinterested. Interestingly, however, the vast majority

of respondents suggested that there was a significant lack of local awareness about the organisations. For example, in Wales there was an adage transmitted from officers to volunteers, and then to new members after the reconfiguration: “CHCs are the best kept secret in Wales”. Similarly, LINK volunteers’ accounts revealed that the absence of a significant nationally-led marketing campaign to promote the organisations affected negatively the recognition of LINKs and their role among local people and professionals as well. Although these specific issues were frequently raised in interviews and during meetings, research informants appeared to overlook their practical significance when constructing their stereotyped images of the public. Some volunteers did consider concerns related to work, family care, personal preferences, mobility and the accessibility of selected venues as potential obstacles for participation; however, as it will be discussed later in the chapter, these practicalities of everyday life were expressed but did not significantly challenge shared organisational meanings of ‘the public’. In the following extract Sally constructed the nature of participation by discussing the problematic attributes of ‘the public’:

Public consultation meetings, which have been so poorly attended [she sighs] and I know it's been discussed about the timing of them, the venues for them, the notifications, where do you put the information about them, but I do guess that that goes back to human nature a bit. As I say, if it's something that's not going to impact on you, people will say 'Oh yeah right', you know, and I don't know how you overcome that...I don't know how you overcome that.

The imagined public was not in a position to challenge the negative inferences drawn by CHC and LINK volunteers about its lack of interest. In turn, as mentioned previously, the physical absence of the public at the organisations’ meetings sustained such beliefs. The use of imagination thus shaped volunteers’ dominant conception of the public as chronically apathetic. Ed imagined that the public saw healthcare as “a difficult subject” and Eden asserted that ordinary people were “only interested in TV and celebrities”. The first claim appears to cast the public as lacking the intellectual abilities to understand the dynamic of the health system; the second one implies a strong moral judgement about what are perceived to be the major interests of ordinary people. Here, TV and celebrities are representations of cultural

decadence which are detrimental to the acceptance of a plurality of interests (Harvey, 2012): in reality, a passion for civic engagement and trivial issues may not be mutually exclusive. Such claims are reminiscent of Prime Minister David Cameron's February assertion that "if you ask children in the UK, all they want to be is pop stars and footballers" (Ellen, 2013). This dismissive statement condemns certain types of interests by suggesting that only a selected category of achievements are legitimate. To use Harvey's words (2012), such claims represented "rhetorical limits" that affected significantly understandings of 'the public'. Furthermore, Daniel constructed the nature of 'the public' by discussing the poor attendance at an open meeting that was arranged jointly by both LINKs as a way to promote the organization, show the work produced and recruit some new participants. He argued:

The only way we would have got a big crowd there to [leisure club] at the open meeting was to co-opt some famous people there, just to, you know, well, not famous but important people there, otherwise people don't wanna know, they won't go out.

When volunteers claimed that "people aren't interested unless something bad happens to them", they created a striking contrast between themselves and 'the public': while they associated their own involvement with positive motivations, the public was perceived to participate only in negative circumstances, which ranged from the lack of services to the closure of a popular local hospital to disease-related needs, such as cancer (often associated to children).

The strategy of presenting very grave instances in support of an explanation recalls one of the rhetorical devices presented by Hollander and Gordon (2006) in their analysis of how social constructions are formed within talks. In this case, some volunteers magnified the gravity of the circumstances that might lead the public to become involved by presenting a narrow array of dramatic scenarios; public behaviour was implicitly considered emotional as a result of this strategy. In both organisations, actors generally drew on the notion of "public outcry" to describe an issue that could motivate ordinary members of the public to participate. Particularly within LINKs, where volunteers were expected to contribute significantly in accord with the requirements of a normal workload (see Chapter Five), these constructions automatically disqualified irregular participation by framing it as a form of

involvement that did not support adequately the advancement of the organisations' work. In effect, volunteers did not acknowledge that the public might, like themselves, become involved on the grounds of positive interests and a desire to contribute to the wellbeing of their own community.

A moral division emerged between volunteers - people making reasoned decisions, helping to build better health services and generally willing to develop an understanding of the key issues affecting a local area - and 'the public', whose key traits were defined in opposition to volunteers. Renedo and Marston (2011) also found that service users in their study perceived to have distinctive positive features as opposed to ordinary members of the public. Only in exceptional circumstances, and when developments would have direct personal consequences, were members of the public likely to mobilise in larger numbers. In the following extract, Pauline constructed the boundaries between 'the public' and a different group of people who, like herself, were genuinely interested in cultivating knowledge:

I think the CHC is doing its bits to try to promote itself, yes, but I think the public only use the CHC when it affects them personally, something has happened, they don't look at it as something to be informed about, do you know what I mean? It's only when something happens 'Oh the CHC', they don't think 'Oh I'd better find out what's happening with the health and the CHC', not that there's any problem but it's just, you know, just for them to inform themselves and be updated on what's happening with the health services etc.

Similarly, Amy asserted that:

I think we do our best in trying to get our name out there [...] but not maybe every, you know, the average people in the public, they probably don't know that much and they're probably not involved in health and social care. I don't know if they would know of LINK.

Blumer (1969) asserts that "the meanings of objects for a person arises fundamentally out of the way they are defined to him by others with whom he interacts" (p.11). In the old CHCs as well as in the new bodies, officers had a central role in communicating representations of the public, which were then adopted by

members. This constituted an interesting point of contrast with LINKs: although the majority of LINK volunteers expressed views similar to their CHC counterparts, there was a striking difference between the perspectives of salaried staff in CHCs and LINKs. Most officers did not stereotype 'the public' on the basis of a sporadic involvement; on the contrary, they were inclined to accept that the public was made up of diverse individuals with complex needs acting within a wide range of everyday constraints. Joyce sought to promote a loose concept of participation:

People can give us much or as little time as they choose or want. Sometimes it might just be, you know, that they will have an awareness raising to be able to have their say and that's all they'll ever do. Other people will feel strongly about something and will come to the LINK and say... 'Are there other people that feel like I do?'

Her view conformed to the DH guidelines, which supported inclusiveness as a key organisational ideal: as a result, this divergence in attitude might be rooted in policy documents, as these represented the context within which salaried staff undertook their role and negotiated images of the public. In fact, LINK employees might find it difficult to present non-participation as a matter for blame, given that DH guidance strongly emphasised that "it is up to you how and when you interact with your LINK" (DH, 2010, p.4).

Furthermore, both in CHCs and LINKs, volunteers' and officers' evaluations of events arranged to convey information or seek public opinion on future service changes were partially based on the physical presence or absence of the public from participative arenas. An event was deemed successful if several people outside the usual circle were in attendance, even though volunteers and officers could not know the extent of the event's impact on people's needs for information and participation. In other words, the public needed to be seen in order to be constructed positively by volunteers and officers. The success of an event hinged on 'a good turn-out'; CHCs and LINKs based their imaginative process on one-off events and the length of the list of attendees they registered throughout the day. We shall return to this point in Chapter Nine, where I use the concept of juridification to discuss how actors constructed PPI in terms of legal duties and used crude proxies, such as counting number of attendees at public meetings, to show that involvement duties were being

discharged. A poor level of participation would reflect badly on the organisations' ability to establish relationships with one of their key stakeholders. Additionally, professionals might not have considered CHCs and LINKs to be fully representative of the public in the absence of the demonstrable involvement of a substantial number of individuals from the local communities.

A few participants provided alternative perspectives on 'the public' and its general attitudes towards participation. Although these understandings ostensibly opposed the meanings conveyed by the majority view, they did not effectively challenge well-established assumptions. For example, when Joey put forth an explanation which examined the complex social context framing involvement, this seemed (unintentionally) to increase the divide between volunteers and members of the public:

You can't expect people to turn up to a meeting or to come and talk to you if you can't have a cup of tea or a cup of coffee, why should they? You know there was an example of that...about two years ago I think it was, whereupon the Assembly wanted to get the views of the public, they held this meeting and one or two people turned up! So they did it again and this time there was a curry night, so they provided hot food, hot curry, for anybody who turned up...In the end they had well over one hundred people!

You know, at the end of the day the public are very busy people and I think that this is something we forget, and the health service does it. When I worked within the GP practice, we used to forget that as well... 'Oh they didn't turn up to their appointment today!' ... 'Oh the public are a nuisance: they never do'...It's a very small part of their day, going to the GP, going to the hospital is a minute part of their day...They may have family to care for or whatever else! Very small part of their day!

Because we're working in it, day-in and day-out, it's on the agenda to us...It's very high that people turn up for their appointments...But how many of us as members of the public...Do we remember we have appointments sometimes? And I'm quite sure if you ask ten people on the street if they have ever missed an appointment for anything at all, they will all come back and say... 'Oh, actually, yes I did!' ...If it's not your work it's not priority to you, it is actually an inconvenience sometimes, so I

think we've got to remember that, it's that the public got lots of other things going on in their life, they're living a life, which is maybe full, maybe active... You know, whatever!

In this long extract, Joey refers to a kind of symbolic exchange to frame the moral context of public participation: the organisation must offer something to people in order to encourage them to become involved and give their time. Joey suggested that this was particularly true for health (illustrated through GP appointments) which was presented as less central to identity construction than were work and family (Bauman, 2000). Joey positioned himself within the group of people who “are working in it day in day out” (the CHC members also seemed to have been included in this group) – that is, in clear opposition to lay people who did not appear to have the same interest in health care. He then attempted to adopt the role of the public (Mead, 1934) in order to demonstrate his empathy and his ability to grasp different perspectives, but immediately switched back to his work role and distanced himself from the public’s attitude. Paradoxically Joey’s sympathetic acknowledgement of the reasons why people chose not to be involved only served to support the assumption that volunteers were different from the general public: the latter needed to be provided with ‘something’ to encourage their participation, whereas volunteers did not need the prospects of material or other immediate gain in order to become involved. At another point in the interview, Joey described members’ motivations for volunteering in celebratory terms and praised their genuine interest in participation by creating and imagined community of dedicated Welsh members:

For nothing back at all, they [members] get nothing whatsoever, they don't get pensions or treatment, they get nothing! All they get is a bus fare home, that's part of their travel expenses reimbursement. Why do they do it? That's a question I wanna know! Why do they do it? Why do they put their names forward? Cause they feel they wanna make a difference, that's why and that's why I respect every single one of them. There's not one, there's not one, any members anywhere in Wales...I think they are all great because they do it because they want to!

LINKs adopted practices, or a reward system, similar to those observed in the Welsh organisations: they also provided refreshments at meetings, and I observed several

instances where Sebastian or other volunteers or employees suggested that lunch should be provided at the end of events or during all-day meetings as a means to attract people. In addition Red LINK wanted to reimburse travel expenses for anyone attending their meetings; in particular, Sebastian viewed this as a way to show people that the organisation appreciated them giving their time. As we shall see later in the chapter, this process contributed to constructing and maintaining competing images of volunteers and the public.

Some other informants imagined 'the public' by seeking to determine what could constitute meaningful barriers to participation. These dissenting were mainly produced in interviews and not at meetings. For instance, to a certain extent Ken endorsed common beliefs constructing the public but partly attempted to offer an alternative interpretation:

How do you get more exposure of these sorts of things to people who are working? [...] Women, you know, they don't have the spare time to drop into the surgery after dropping the kids to school because they gotta rush straight off to work, so you know it's much the same thing and they're probably finding it harder. So you know, as far as the groups that are around all the time, it's probably relatively easier as long as they know it's there but then the people who aren't around, they don't know it's there. But you've got no opportunity to expose them to the information that is there, if you see what I'm saying, so you've got a double issue I think.

In another example, Sebastian, the Red LINK chair, fully endorsed the view of health as "something which is kind of not seen as very sexy"; however, he acknowledged the importance of offering alternative forms of participation that sought to capture the wide range of personalities and needs among the population:

We have to find ways of allowing people to express themselves rather than coming to meetings because meetings aren't for everybody... You know some people wanna write poetry about it, some people wanna make a sculpture about it, some people want to paint or draw about it, so it isn't just about sitting at meetings. You cannot engage people fully just by saying you got to come to meetings, because there are people who don't wanna go to meetings.

Sebastian suggested several other initiatives within observed meetings, although the majority of volunteers in the management group sometimes vetoed his proposals. He made sense of the disagreement within the management group by arguing that “the difficulty we have is that some of the old PPI people are very traditional [...] I think to engage with the wider audience you have to think slightly more creatively and more outside of the box”. For example, he advised involving Red City Football Club to promote awareness about testicular cancer, an idea which was not approved by the management group since some volunteers argued that it was unclear how the proposal fitted in with the LINK’s remit. Sebastian also suggested that the development worker should engage with a group of local young people and provide them with a large board to express their experiences in relation to health and social care through paintings. Furthermore, he got the management group to fund a limited series of LINK-branded give-away items such as key-rings, recyclable shopping bags, and Post-it notes that could be distributed at local events. Sebastian wanted to gain the public’s attention and promote interest in the LINK by seeking to enter people’s everyday life. In a communication group meeting he also suggested organising a trolley dash competition a few weeks before Christmas in collaboration with a popular supermarket chain. Sebastian’s ideas aimed to raise awareness about the LINK by seeking to capture different segments of ‘the public’, and seemed to evoke his professional background in photography and marketing. He was also a mental health service user himself, and had wide experience with others suffering from severe mental health conditions. His background was reflected in his participatory strategies, which embraced a wide idea of the public and its constituents.

Also other informants in both LINKs and CHCs, such as Emma, Tyler, Sally, Lucy, James sought to provide alternative explanations as to why members of the general public would not participate (in relation to working hours, lack of awareness about the proposed events and lack of confidence to attend public meetings); however, these represented only weak perspectives that were mainly mentioned in interviews instead of being discussed during meetings. As such, these different views did not hold a pragmatic relevance in reshaping widely accepted assumptions on ‘the public’.

Joyce drew on a different argument to discuss local involvement in Greenshire with regards to social care services:

Joyce: If you look at the LA providing social care, they're an authority which has what they call four stars so when they're inspected, they are inspected as a very good LA, and I'm told that you know most people are very happy with their services [...] Because people think this is a four stars LA and things are good...I don't know whether that means that they don't join mmh...

SS: so this four stars assessment, that can be a reason...

Joyce: well that's what people have told me it's the reason...we've got a good LA so...

She was quite cautious in fully accepting such an explanation to justify a poor involvement of local people in Greenshire LINK's activities related to social care services. However, she drew on this reported account in interview and also in some observed meetings where they were debating practical obstacles to involvement.

Broadly, the public was regarded as disinterested by those who were themselves engaged in LINKs and CHCs. Only a few individuals attempted – unsuccessfully - to offer alternative images of 'the public' by considering a wider range of aspects and the social context of involvement. In the next section I describe the dynamic nature of the constituted public and how negotiated characteristics emerged from the interaction of local understandings, practical decisions and legal boundaries that framed the organisations' work.

Who is the public?

Through everyday activities and practical decisions, CHCs and LINKs constituted groups of people that became their 'publics'. In effect, the nature of the public was also shaped by top-down guidelines combined with officers' need to negotiate sustainable working practices for the organisations.

During fieldwork, I soon realised that CHCs' work was broadly organised according to heavily routinised work patterns which, among other things, aimed to ensure that

members were able to participate fully. Officers posted papers to volunteers, and to myself, at least one week before the actual meetings dates. Meetings were regularly held in the same venues; Alexandra, Rainbow CO's PA, booked their meeting venue in advance for the whole year. Both CHCs usually met in a hospital boardroom, an LA meeting room and/or, where possible, a spare room within their offices. Alexandra explained to me that the venues were selected because the NHS or the LA allowed the CHCs to use them for free. Before the reconfiguration Blue CHC held regular meetings in its office in Trees Area (see Chapter Four) which was not accessible to people with impaired mobility and did not have an adjacent fully accessible car park. Most importantly, however, a car was necessary to get there as buses were very irregular. The need to operate within financial constraints and to sustain orderly working practices pre-empted negotiations on accessibility issues, which would have ensured that the organisations demonstrated attention to inclusiveness and equality. In practice, the physical absence of people exhibiting different needs meant that these groups were left without a voice.

CHCs attempted to establish communication with 'the public' in different ways. Alexandra was extremely efficient in updating information on the CHC website about dates and venues of meetings, minutes, agendas, reports of monitoring visits and various written exchanges between the CHC and other bodies. Difficulties in retrieving the information were associated with what Joey defined the "convoluted web addresses" of CHCs: these were in fact related to a general directory (www.wales.nhs.uk), and carrying out a web search may have required some preliminary knowledge of the existence of such citizen-engagement organisations. The information available on the Blue CHC website was mostly out of date as Esther only began to update the site a few months after the reconfiguration; in the meantime, one could not tell whether the organisation was still operating. Overall, the work of the old Blue CHC addressed mainly patients within health services; the public was only mentioned when volunteers and officers referred to past public consultations wherein the CHC agreed with NHS plans while the public expressed contrasting views. In Blue CHC actors appeared to sustain routinized organisational arrangements rather than engaging in reflexivity to challenge assumptions and potentially redefine working practices in complex social contexts. Informants

described a few activities aimed at local people, such as standing outside the hospital or in the bus station “with our banners”, as Esther explained, and a top-down initiative called Awareness Week, aimed to promote the CHCs and their role within the local communities.

In contrast, Rainbow CHC officers aimed to make the organisation much more visible by holding what participants variously referred to as regional meetings or Public Reference group (PRG) meetings. These were held in the four PRGs established in four different areas of Rainbow City. Simon explained:

With the members, [there were] six in each PRG by and large where they lived so they were part of the community anyway, and that's how it tended to work. So they could not only listen to what the public were saying about the proposal or a service, they could ensure that the NHS managers came and the accuracy of the information that was given over by those managers.

Both officers and volunteers were very keen to talk about these meetings: it seemed that they wanted to emphasise the symbolic importance that the initiatives once held for the organisation. They described PRG meetings held in Moon (an area of Rainbow City) as particularly successful. Janice described them as “lively meetings, very, very good actually, and you get the GPs coming as well as the general public, sixty-seventy which is fantastic you know - and then they listen, they do”. Such general enthusiasm related to the significant turn-out featured in the process of construction of meanings of PPI, and will be discussed in Chapter Seven’s examination of participants’ legal interpretations of involvement. PRGs in other areas, however, “didn’t really work very well”, as Janice revealed. Echoing other volunteers’ concerns, she was puzzled as to why people in those areas did not participate:

I don't know why, we wondered why because, you know, Joey used to turn up, Simon used to turn up, I used to turn up and the local people, the local voluntary people used to turn up and [she chuckles] we sat there...Every time of the day we tried, they just weren't interested. It was interesting actually but [...] They used the services but they weren't interested in coming to listen, learning a bit more and give their opinions on how the services could be improved.

Informants recounted that these meetings were promoted through leaflets pinned up on notice boards of local buildings, and through word of mouth. Despite the CHC imagining and attempting to consider the potential needs of local people when arranging the meetings at various times, people still showed a lack of interest in contributing to their improvement. Janice drew a comparison between the successful activity in Moon area and activities in other parts of the city: the former was in the process of being redeveloped, and had received LA funding to restructure certain primary care services. She contended that, because of the major changes occurring at that time, people were interested in receiving information on how their daily use of health services would be affected. She also expressed a common view that people become involved only “if interested” or “only if it touches them”. This equation reinforced volunteers’ disappointment and, most probably, sustained imagined assumptions about the public.

After the reorganisation, CHCs were strongly encouraged to find ways to engage with hard-to-reach groups, which, according to Ministerial suggestions, included Black and Minority Ethnic (BME) populations such as young people, and the homeless. Officers’ interpretations of Ministerial suggestions shaped and to a certain extent ‘filled’ with top-down imposed meanings the very notion of ‘the public’, even though the key qualities defining the “hard-to-reachness” of such groups were not conceptually manifest (Mackenzie et al., 2012, p.2). In practice, there were broad assumptions about the composition of hard-to-reach groups, which were related to common-sense understandings of social exclusion from the use of health services. Interestingly, I did not observe any research participants attempting to address this lack of conceptual clarity when using the concept of hard-to-reach groups to plan and implement PPI.

CHCs had to manage the requirement to comply with Ministerial guidance and the need to verify whether the target groups mentioned were actually accessible in their localities. PPE officers contacted well-established local groups that could help to engage with organisations dealing with hard-to-reach demographics – such as Communities First, the Big Issue and Shelter. Esther, for instance, discovered that Blue City and Hill Town provided night shelters only during the winter months. As a result, she worried that she would not be able to sustain regular contacts with hard-

to-reach people and particularly with homeless individuals, who were targeted for CHCs' engagement activities. After a strenuous search, she explained that she managed to arrange a meeting with "a girl who's doing something on homelessness, she doesn't explain exactly what so she wants to see if we can work together". Esther had high expectations for this meeting: she hoped to advance the CHC's work in line with Ministerial guidance by securing a contact that would enable her to engage "in winter time when we will have the shelters so we'll be able to go out and see what's going on". In general, officers worked hard to find appropriate individuals evidencing that they established a contact and that, like in this example, they identified a virtual group of homeless people.

However, negotiations occurring with local groups in order to adhere to Ministerial guidelines should be analysed in view of local contingencies. CHCs might operate in areas offering services and activities reflecting the diversity of service provision and the geographic characteristics of Wales. Neglecting these circumstances may have led officers to concentrate on finding a group of people to evidence that the CHC was complying with its duties and meeting national expectations to show commitment to PPI. Pressure to identify the same hard-to-reach groups in every CHC area might also have derived from the All Wales PPE Forum, a national body composed of PPE officers and Deputy COs. When I attended one of the initial meetings, I realised that the Forum represented a way to share knowledge, learn from each other's working practices and, particularly, to ensure that CHCs worked consistently across Wales, so that they could present standardised evidence of their activities. In that meeting, I observed officers discussing the need to engage with the Polish community, which was seen as one of the key hard-to-reach groups, although one CO remarked that he was not aware of any formalised group of Polish people in their area. In a way, local officers may have been encouraged to find services and groups of people that reflected the hard-to-reach nature of target groups (Mackenzie et al., 2012) as communicated by the Minister.

Similarly, Red LINK had to comply with top-down requirements that defined the composition of 'the public': in fact Red LA identified various groups which they expected the LINK to prioritise when doing engagement. As a result, Helen planned her work to adhere to such guidance:

We were told that at least 50% needed to be women - that's not been very difficult. 20% needed to be disabled people and 20% from BME communities so I've tried to prioritise a bit...If I go out to visit groups, I try to target some of the BME groups to work with....and disabled people as well as one of the groups to go to also. I think we're falling short on BME participants; that's something definitely we need to do a bit more work on.

Although the LA's decision probably aimed to foster the values of inclusiveness and equality, its implementation arguably resembled a tick-box exercise rather than a reasoned assessment of local groups in need of outreach efforts. In doing so, the LA promoted a reproduction of static categories instead of enabling a bottom-up-led inclusion of groups: this process arguably affected the organisations' autonomy in planning PPI and it shaped the idea of involvement as mainly determined from above. In practice vague definitions - e.g. the disabled - may become meaningless, and may result in actors having to negotiate arbitrarily specific characteristics to regulate access for some social groups. Furthermore, my data suggest that nobody sought to renegotiate, or resist, this form of control imposed by the LA.

On the other hand, volunteers and officers generally described Greenshire LA as "very relaxed" since it did not officially impose any criteria for the selection of groups forming the public. However, Gary was highly influential in facilitating connections between the various working groups (particularly the core group) and local communities. Probably drawing on his personal experience of living in an isolated village in Greenshire, he decided that "from the very very start, almost three years ago, that each of our meetings moves every month to allow different groups to have their say". In fact, he imposed this view upon the LINK expecting the core group to meet in every single locality in Greenshire in order to enable people from rural areas to attend the meetings and encourage them to report first-hand experiences of health and social care services. Although other informants approved Gary's strategy in principle, they also criticised it to a certain extent by framing his beliefs within a broader organisational context. It was rather costly to finance volunteers' transport, especially taxis, to the designated venues due to size of Greenshire area. The perceived lack of adequate financial resources severely affected judgements regarding the feasibility of engagement activities and, more generally,

what the LINK could accomplish in everyday work. Additionally, some volunteers argued that a combination of factors (such as winter weather, evening meeting times and venues located in remote areas) might prevent people from participating. I observed a few meetings where some volunteers claimed to have gotten lost on their way, and some professionals did not manage to attend because they either struggled to find the venue or, given their tight schedules, realised they could not drive to the venue in time from their NHS base.

Having identified potential groups reflecting imagined understandings of the public as influenced by top-down guidance and internal negotiations, LINKs and CHCs had to develop and implement a communication system to reach out to these groups. LINKs were very keen to provide as much information as possible about their activities. The organisations' websites provided a detailed account of the range of work undertaken as well as several links to reports and external sources on health and social care. Meetings were generally advertised through leaflets and posters pinned in the selected venues (which were usually community centres), but also through monthly LINK newsletters and, in principle, volunteers themselves were expected to "spread the word", to use Gary's words, about the organisation's activities through their local connections. The varied composition of LINKs in relation to ethnicity, socio-economic characteristics and accessibility needs ensured that venues selected for meetings were fully or at least partially accessible. In fact LINK participants exhibited a range of social and physical conditions: some had cerebral palsy, while other had mental health issues and still others had impaired mobility or hearing. The English bodies arguably appeared to address several practicalities to promote greater participation. For instance, in selecting barrier-free environments they shaped a largely inclusive notion of 'the public', which emanated from insiders' own needs and experiences. In addition, some working groups even decided to identify popular local venues in certain areas of the LA in order to attract particular groups of people as well as to show a particular interest "in going to people", as Joyce liked to argue. For instance, volunteers and host organisation officers claimed that some areas in Red City were mainly inhabited by BME people, and they tended to arrange the equality group or involvement and engagement group meetings within these identified territories. They assumed that the themes discussed

in the two groups would be particularly suited to establish preliminary connections with BME individuals. Furthermore, by offering meetings “on their doorstep”, as Sebastian explained to me, LINKs hoped to increase the likelihood of attracting people from this demographic who fell into the categories identified by the LA.

These situated constructions of the public were also reflected within observed meetings, which acknowledged a virtual space for the public. The agendas of LINKs management groups included a ‘public forum’ slot, which anyone could use to voice a perspective or to make a specific request; this was usually the second item on the agenda after ‘minutes and matters arising’. In principle, people raising issues could then remain for the whole meeting if they so wished. Throughout my fieldwork, this slot was mainly used by people already involved in LINKs, mainly as participants of working groups, and I never observed a complete stranger attending this session. While the public voice was therefore made visible in the organisation’s formal agendas and minutes, it is debatable whether people not involved in LINKs were aware of this opportunity. Red LINK’s volunteers particularly welcomed this approach, which regulated and to a certain extent limited the degree to which ‘the public’ could have input into the work of the management group: agendas usually covered several topics and the two hours available always seemed insufficient to deal with all the items. Interestingly Tanya, a Red LINK volunteer, argued that the “public forum” slot also functioned to limit ‘the public’s’ access to some discussions in the management group:

Tanya: Because anybody can come to a LINK meeting, they can’t always participate but they can observe, at every meeting there’s an opportunity for the public forum before the main business of the meeting begins.

SS: But why did you say that people can come here and observe, but they can’t always participate?

Tanya: Well, they can’t participate because they’re not members of the particular subgroup and they may not have the expertise, it’s not that we don’t want them to, but...Some of the stuff is quite confidential as well, and the general public might be

asked to leave at some point...not for anything but just...you know, just...because they're only very loosely involved.

In principle, regular volunteers could thus prevent 'the public' from participating fully to some discussions and gaining some information in view of the nature of their loose involvement that did not allow people to establish a solid rapport with the management group. As illustrated in Chapter Three, in effect regular participants sanctioned flexible ways of participation and made sense of the network as an organisation with a formalised structure.

The 'public forum' slot was not officially included on CHC meeting agendas. On a few occasions, I observed local people attending a regular CHC meeting: in these cases, the Chair controlled the discussion by offering individuals the opportunity to comment on the issues under debate.

Officers and volunteers also created 'the public' through the physical arrangement of space, which regulated how potential attendees could occupy the meeting room. LINK staff always ensured that the door was open until the meeting actually started, and Rachel also opened the windows and front doors of parish halls and villages community centres to make the LINK's presence visible and hopefully attract last-minute local attendees. At a meeting in February she noticed I was quite cold and she said "I hope you are warm enough, sorry, Silvia, but I wanted to make sure that everybody got the feeling that they are more than welcome to take part in our meeting". She regularly encouraged the participation of local people by promoting a symbolic sense of belongingness. Additionally, salaried staff always ensured that extra chairs were available to accommodate any attendees who arrived last-minute. When this happened, I observed both volunteers and officers helping to arrange the chairs around the table so that new individuals could mingle with other people in attendance. LINKs were established as networks wherein actors were regarded, in principle, as equal in the imagined space of participation.

In contrast to the LINKs, Blue CHC did not devise any strategy for symbolically encouraging people to participate. As shown in Chapter Four, their meetings before the reconfiguration mainly reproduced past patterns of work in the old organisations rather than attempting to open up spaces to expand participation outwardly. Before

council meetings, Rainbow CHC officers usually welcomed members as well as the very few members of the public that I observed attending these council meetings. What the two CHCs had in common, however, was the physical positioning of 'the public' within meetings: people were usually allocated spaces in a separate area of the room which created a clear distinction between them and the CHC membership. As recounted in Chapter Two, I experienced myself such a distinction in my observations of Blue CHC, when I was sometimes asked to sit at the back of the room, isolated from the physical centre of the interaction. CHCs were councils composed of appointed members and their legal status contributed to shape an exclusionary sense of belongingness.

The public 'out there'

As we have seen thus far, conceptions of the public were constructed in interaction while informants were making sense of their role and were seeking to comply with top-down instructions regarding the groups targeted for involvement. The public was an entity whose composition and qualities varied across the organisations in response to contingent circumstances. Informants transformed the public into an object, or an independent entity 'out there' – that is, distanced from the work of the organisations. Further, development workers or CHC officers described one of their roles as 'getting out there'. The strong emphasis placed by participants upon the spatial placement of 'the public' is sociologically interesting in that it shapes the construction of the organisation's sense of identity as far as roles and responsibilities are concerned.

The symbolic character of people 'out there' highlights a complex definitional scenario. As illustrated earlier, the majority of volunteers distanced themselves from 'the public' since they saw themselves as committed citizens contributing to improve the common good. Volunteers defined their sense of self in relation to how they understood their role: their accounts generally suggested a sense of discomfort in aligning themselves with people that belonged to a contested public realm. For instance, in an interview Andy referred to 'the public' or 'the man in street' as groups of people with whom he did not feel affiliated and from which he actually

distanced himself. Max asserted he could not speak on behalf of the public because “from a public perspective, I don’t really know”.

Some LINK volunteers defined themselves as part of the general public to a certain extent, but this seemed to be more a rhetorical device than a firm belief. Sheila drew on the same terminology as Andy, but added that “we [LINK volunteers] have no qualifications, we are lay people”. Charlie, an active participant in Red LINK, claimed that “it’s all apathy, tremendous apathy” and somewhat presented himself as an advocate for people’s rights and a defender of the British welfare state. Informants appeared to suggest that they drew on “a distinctive framework of symbols” (Day, 2006, p.161) to negotiate a specific sense of belongingness to imagined communities of people sharing the same civic commitment. These communities transcended the geographical boundaries of an LA or a PCT; rather, they were rooted in individuals’ sense of self in perceived opposition to the public. The following data extract illustrates how Emma constructed people ‘out there’ in opposition to how she made sense of her role by drawing on common sense images of local shoppers:

I think the vast majority of people you know, and again if you go to the Sainsbury shopper or Tesco shopper or whatever, what they expect is to have the opportunity to be consulted, but they wouldn’t necessarily want to be...involved in what’s happening.

Further, CHC members tended to draw on reported or first-hand experiences of being a patient as a crucial asset for making sense of their role, although some of them also acknowledged the multiple capacities in which they acted (CHC volunteer, member of the resident association, retired professional). In the vast majority of cases, volunteers held multiple affiliations – the CHC, other voluntary organisations and their local communities – although particularly the Welsh officers expected “the CHC hat” to override affiliations with local areas or groups. It is relevant to illustrate that the CHC role may be explained through the concept of master status (Hughes, 1945): that is, a status that overrides statutes associated with other roles. The CHC membership was acknowledged as the dominant characteristic of individuals; arguably, officers, and pre-reconfiguration members, acted consistently in order to establish symbolic boundaries between themselves and ‘the public’. In doing so,

volunteers could thus comply with expectations of roles as discussed in Chapter Four. As illustrated in relation to the example of the hospital in Sun town (see Chapter Four), the need to remain emotionally detached from emotive issues related to local health services represented a key quality reflecting members' master status. Also in other public consultations wherein Blue Sand Hill CHC was involved, it was argued that patients' safety was at stake and members had great responsibility in safeguarding it by making decisions informed by objective criteria and an appropriate state of mind, otherwise local people could be seriously harmed. This capacity for neutrality created a symbolic divide between members and 'the public'. As anticipated in Chapters Three and Four, NHS and LA professionals also expected volunteers to conform to this personal attribute.

Negotiations concerning organisational identity may be better framed using Goffman's (1959) concept of impression management. CHCs and LINKs wanted to emphasise their credibility through a visible detachment from the NHS by acting in ways that reflected this view. In observed meetings, I realised that Rainbow CHC expressed this idea by designating a separate seating area for professionals. The other three organisations did not implement any similar seating arrangements, choosing instead to construct the trait of independence through communication. At the same time this image had to be carefully balanced with the need to work in partnership with professionals and acting as their critical friend, without jeopardising the credibility of the CHC. In Chapter Seven I will discuss how informants' negotiations enabled the organisations to sustain relationships with professionals. Interestingly, although CHCs and LINKs did not have high regard for 'the public', public engagement remained important for the organisations to show they were functioning as policy makers intended.

Are there counterpublics?

In developing an interactionist account of constructions of the public, it is important to avoid presenting a picture of shared meanings and total consensus that glosses over the disagreements and struggles over definitions that can sometimes occur.

An important group of authors (e.g. Fraser 1990, Warner 2002 and Wittenberg 2002) from the rival theoretical tradition of critical social theory (CST), attempts to relate the public sphere and conceptions of the public more explicitly to the unequal power of different groups. Without taking on board theoretical assumptions from CST that would compromise my interactionist position, I want to consider in this final section whether actors in LINKs and CHCs do sometimes construct reality in a way that questions the 'representativeness' of some groups or marginalises their voices.

To understand the theoretical basis of the CST critique we need to recall that Habermas et al. (1964) defined 'the public' as a group of private people gathering to discuss issues of "general interest" (p.49). To do that, individuals need to reach consensus in debate, and their various interests and social differences are not expected to emerge from their talk. Fraser (1990) argued that Habermas' idea generated a type of discussions where "inequalities of status were bracketed" (p.59). Fraser argued that groups excluded from Habermas' bourgeois public sphere might succeed in creating their own public spaces. She discarded Habermasian ideas of consensus and homogeneity whilst proposing the formation of "subaltern counterpublics" (i.e. subordinate, p.67), portrayed as "parallel discursive arenas where members of subordinated social groups invent and circulate counter-discourses, which in turn permit them to formulate oppositional interpretations of their identities, interests and needs" (p.67). Fraser's (1992) argued that dissimilar interests and social differences cannot be excluded from the public sphere, but instead must be included in discussions to reflect the wide range of stakeholders' perspectives.

As an example of counterpublics, Fraser (1997) put forward disabled people and their supporters, who she suggests have become marginalised groups, thus leading to "a widening of discursive contestation" (p.67). Gibson, Britten and Lynch (2012) also discussed disability groups as an example of counterpublics. Similar to Fraser

(1992), Warner (2002) suggested the idea of counterpublics as groups of marginalised people. He defined the discursive nature of publics and counterpublics as equally “notional as empirical” (p.414) and that “it exists by virtue of being addressed” (p.413). Like Fraser’s counterpublics, Warner’s counterpublics allowed “members’ identities [to be] formed and transformed” (p.424). For instance, becoming involved in a Disability Forum or in a local LGBT group allowed participants to elaborate reflexive arguments on their subordinate status with respect to mainstream groups and how the latter might fit into the broader social context. This process could provide an opportunity for marginalised groups to challenge and alter established discourses and practices (Barnes et al., 2003). If these studies have validity we could expect some of these processes to be visible in interactions within LINKs and CHCs.

Although my interactionist framework differs from the theory underlying these studies, there were indeed processes at work in LINKs and CHCs that defined some groups as more representative of the ‘public’ than others, and distinguished between the insider identities of regular participants and the identities of participants seen as being more marginal to the core work of the organisations.

Volunteers were first and foremost potential users of health care services, and were expected to draw on this general assumption in the performance of their roles. However, in accordance with Fraser’s view, some volunteers proposed different understandings of their role (see Chapter Five and Six), which clashed with routinized working practices and established insider perspectives. Many LINK volunteers as well as some post-reconfiguration CHC members interpreted their organisation as a forum wherein they could discuss issues reflecting personal interests and individual differences in terms of disability, ethnicity, gender, sexual orientation and/or socio-economic status.

This might cause concern among insiders who often dismissed these views as those of ‘single issue’ participants. For example, in an interview Carrie made sense of the post-reconfiguration context:

SS: Can I just ask for a clarification because I don’t think I got the meaning of what you said...You talked about single issues but I mean what do they involve in practice?

Carrie: The easiest example to give you is disabled: they force the disability agenda without considering the other issues, without considering the financial situation. They tend to get very parochial and indeed some of the [local] councillors who are relying on their next vote to get into power can also be very parochial and vote for something which is popular with the voting public, rather than what makes sense in the health world, all right? I mean, in an ideal world we'd want every city to provide every facility, at a perfect level we know that's not possible, so it can be a bit emotive.

Although this extract illustrates concerns expressed in that specific CHC, Carrie's arguments are relevant to the other three organisations, albeit to a more limited extent. She suggested that supporting disabled people (a group exemplifying a set of particular needs) in fora like CHCs was acceptable only to the extent that it did not obstruct regular working practices and it did not challenge the definition of health normally used. However, when disabled people were perceived to make requests beyond a reasonable limit, their involvement appeared to threaten the stability of the organisation and as such raised concerns. Tyler shared a similar view at a meeting organised by Red LA to discuss how the NHS reforms would affect the organisational structure of Red City health and social care services. Sebastian was the last speaker at the event and he encouraged a debate about the threats and opportunities brought about by the introduction of LHW. The following extract from my notes shows how Tyler's comment echoed Carrie's concern with narrow sectional interests:

During Sebastian's session, when he wanted participants to discuss threats and opportunities about LHW, Paul came in and said he was worried about the name Healthwatch – he argued it could be misleading and could leave social care out. Tyler, sitting next to me, shook his head and had his (well-known) expression of disapproval on his face. I thus asked him "Do you think this is likely to happen?", and he said "No, it's not, he's just representing a vested interest".

As described in Chapter Five, Paul had cerebral palsy and was regularly involved in a Red LINK working group looking at social care issues; in addition, he was committed to promote knowledge and practical consideration of the social model of

disability. As such, his concern was interpreted as a manifestation of a 'vested interest' rather than a genuine reservation regarding the effect of the new legislation on local people's involvement. In addition, the extract from my notes, as well as the statement from Carrie's interview, echo Fraser's (1990) dilemma: "we should question whether it is possible even in principle for interlocutors to deliberate as if they were social peers" (p.65). As I have detailed in Chapter Six, after the reconfiguration the presence of new members, with dissenting voices representing issues that CHCs appeared not to have considered before strongly highlighted the need to manage these differences and integrate them into the daily work of the bodies.

Volunteers like Gabriel, Anne, Rose, Amber, or Paul strongly advocated for a positive recognition of difference as a means of acknowledging a diversity of needs, and acting upon them in undertaking regular work and ensuring that the organisations guaranteed equal access. Overall though there was a continuing tension between those insiders who saw representatives of particular user groups as key players in promoting engagement, and those who used the label of 'single-issue' status to resist giving them very much attention. Thus although I stop short of embracing the concept of counterpublics, LINKs and CHCs were undoubtedly forums in which representatives of specific user groups, some of them marginalised groups, could negotiate to have their voices heard, albeit with varying degrees of success.

Conclusion

In this chapter I have explored negotiations about the meanings of 'the public' by considering the institutional frameworks and social contexts within which CHCs and LINKs operated. I have described how informants reached understandings of the public, which were generated in opposition to a construct of the volunteer's role as an ideal of civic participation. I have also shown that 'the public' was seen as an empty receptacle which was eventually 'filled' by a combination of interpretations of statutory duties, pushes such as the Minister's instruction to engage with marginalised social groups, and the local availability of groups fitting into the broad hard-to-reach category. Informants were expected to address top-down expectations,

which were interpreted as static structures that guided and shaped decisions regarding the social groups to target for outreach. As a result, this process limited opportunities for the organisations to expand discussions and develop more nuanced concepts of ‘the public’ that acknowledged diversity and actively supported the varied nature of people’s needs. My data showed how some informants sought to propose alternative and more inclusive perspectives about ‘the public’ and its poor involvement with CHCs and LINKs; however, such arguments did not significantly alter established views.

In addition, I have considered theories concerning the public sphere, and pointed to an ongoing tension between the requirement for LINKs and CHCs to engage with certain disadvantaged groups and the tendency to devalue the contribution of ‘single-issue’ participants. New CHC members and irregular LINK participants representing particular service user groups were considered unable to adapt to existing understandings of roles and organisational practices. In effect, this chapter has demonstrated how actors endeavoured to reconcile regulatory frameworks and local interactions in the attempt to sustain understandings of the volunteers’ roles and perceived organisational responsibilities.

The processes via which informants constructed the public may lead to multiple negative outcomes. People may be excluded from participation and be deprived of opportunities to express their needs, which in turn may create narrow definitions of health care and social care issues that do not capture the multi-dimensional experiences of people in a local area. Furthermore, in the majority of cases CHCs and LINKs dictated the rules of how to participate (although particularly Red LINK attempted to offer unconventional modes of participation) by imposing formats that may have facilitated, or limited, access for certain groups of ordinary people. The nature of the symbolic boundaries between volunteers and ‘the public out there’ might thus reinforce social boundaries to the point where operative strategies might limit inclusion and participation. These aspects shaped the planning and implementation stages of PPI, as we shall explore in Chapter Nine.

Informants’ constructions of the public also revealed the former’s perspectives regarding the value of participation. Despite different organisational arrangements,

the analysis showed that research informants of both CHCs and LINKs understood and acted upon near-identical notions of imagined communities; volunteers' accounts suggested that they saw themselves as part of an imagined community of active citizens, albeit with certain specialised skills and knowledge, which thus transcended the physical boundaries of a community and formed an idealised notion of an active citizenry. Actors also seemed to mobilise the idea of community as a symbolic resource (Cohen, 1997; Day, 2006, Chapter Six) to build a collective sense of belongingness. The present chapter, supplemented by the analysis of Chapters Five and Six, has evidenced a symbolic divide between the volunteer's role and that of ordinary members of the public.

This chapter advanced empirical knowledge of the social and organisational contexts in which actors made sense of PPI as set out in Chapters Five and Six. The next chapters will draw on previous discussions to illustrate how conceptions of roles and relationships and images of 'the public' affected the process of construction of meanings of PPI from planning to implementation. Particularly, in Chapter Eight I will discuss the regulatory frameworks that regulated PPI within England and Wales, and will explore how local stakeholders interpreted PPI in everyday practices. In Chapter Nine, I will illuminate the negotiations through which local actors made practical decisions about PPI and how they were expected to navigate a complex network of roles, which originated from the task to 'do PPI'.

CHAPTER EIGHT

UNDERSTANDING PPI: RULES, EXPECTATIONS AND INTERPRETATIONS

PPI can be absolutely huge, it can be absolutely massive¹.

Introduction

This chapter considers the framework of rules and organisational practices that influenced understandings of PPI and how these were interpreted by officers, volunteers and NHS professionals regularly involved in LINKs and CHCs. To this end, it examines the Welsh and the English statutory provisions affecting PPI and employees' and volunteers' responses to these. It also presents the legal framework within which the role of the LINK development worker and that of the CHC PPE officer emerged to comply with top-down expectations; additionally, the analysis discusses the learning opportunities created within the organisation. Furthermore, it discusses how involved stakeholders – volunteers, officers and NHS and LA professionals – understood PPI in relation to their organisational roles and existing expectations about the nature of their work. These concepts of distinct mechanisms of participation have been widely discussed in the literature in relation to whether involved individuals are conceived as citizens or consumers (Greener, 2009).

Chapter Nine complements this analysis by examining how actors used their understandings of institutional frameworks to define the nature of their particular roles in PPI organisations and to negotiate how 'to do PPI'. Both this chapter and Chapter Nine draw on the previous empirical chapters to examine the extent to which meanings and decisions were influenced by relationships and everyday interactions involving volunteers, officers, professionals and members of the public.

As noted in Chapter One, I will use the term PPI as shorthand for various related developments in public policy since the 1990s. This use of a single term is not

¹ Quotation from interview with Ed, the first CO of Blue Sand Hill CHC.

intended to deny the multi-dimensional nature of the concept of PPI (Anderson et al., 2006; Baggot, 2005; Tritter & McCallum, 2006): I will respect informants' language by justifying the introduction of a different terminology when appropriate.

The chapter is divided into the following sections: first, I will examine the legal rules and associated guidance regarding PPI as pertaining to CHCs and LINKs. I will also describe the role of dedicated officers invested with the responsibility of 'doing PPI'. Next, I will discuss the processes of social learning that developed in relation to PPI, and show how LINKs attempted to address participants' personal development as a way of bolstering volunteers' roles. I will then explore conceptions of PPI as understood by volunteers and salaried staff, and will relate this aspect to the processes of roles construction examined in Chapters Five and Six; NHS and LA professionals' views will be presented in a separate section.

Legal provisions regarding PPI for LINKs and CHCs

Since 1974 the UK government has developed citizen-engagement organisations as part of a wider plan to redefine relationships between citizens and public service organisations (Hughes et al, 2009; see Chapter One). NHS bodies in both England and Wales have been subject since 2003 to a general duty to involve and consult the public, as set out in Section 11 under the 2001 Health and Social Care Act. Section 11 was amended by s. 242 (1b) of the National Health Service Act 2006 and later by s. 233 of the Local Government and Public Involvement in Health Act 2007; the latter requires that

relevant English bodies must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways) in (a) the planning of the provision of those services; (b) the development and consideration of proposals for changes in the way those services are provided, and (c) decisions to be made by that body affecting the operation of those services.

A similar duty also applies to relevant Welsh bodies. S. 183 of the National Health Service (Wales) Act 2006 requires LHBs and Trusts to involve and consult citizens in the planning, development, operation and changes to services they provide or procure.

However, controversy has arisen concerning the extent to which the new English PPI framework associated with the formation of LINKs has been accompanied by a strengthening or weakening of the old duty to involve and consult. The DH has presented the 2006/2007 legislation as extending involvement in, for example, operational decisions and major service changes, and as introducing a new duty for PCTs and Strategic Health Authorities (SHAs) to report on how consultation influences commissioning decisions. In 2008, the DH published “Involving people and communities: a brief guide to the NHS duties to involve and report on consultation”, which states that “this duty [the duty introduced in 2003] to involve has been strengthened” (p.2). This guide is not limited to “users”, but rather encompasses abstract groups such as “communities” and “people”, which ostensibly broadened the scope of involvement. Nevertheless, Mullen et al. (2011) have contended that the Local Government and Public Involvement in Health Act narrowed the scope of consultation. The scholars argued that

The revised duty under the Act retains the requirement for involvement in: (a) ‘the planning of the provision’ of services; (b) ‘changes in the way those services are provided’; and (c) ‘decisions...affecting the operation of those services’. However, this is now subject to the condition that parts (b) and (c) only apply if proposals would affect ‘the manner in which the services are delivered to users of those services...at the point when they are received by users’, or ‘the range of health services available to those users’ (s. 233 of the 200 Act) (p.31)

In addition to the examination of statutory frameworks for PPI, it may also be instructive to provide an overview of the statutes that created CHCs and LINKs. CHCs were established in England and Wales by Section 9 of the National Health Service Reorganisation Act 1973: the key duty of such bodies was “to represent the interest in the health service of the public in its district”, meaning that CHCs were required to be coterminous with Health Authorities’ boundaries. The Health

Authorities Act 1995 amended this section, and also the provisions of the National Health Service Act 1977, by stating that CHCs were no longer required to be coterminous with Health Authorities. Seven years later, the National Health Service Reform and Health Care Professions Act 2002 established PPI Forums which replaced CHCs in England, whereas Wales retained CHCs and in 2004 expanded their roles (Community Health Councils Regulations 2004/905). However, the Local Government and Public Involvement in Health Act (2007) amended the previous provision by establishing LINKs in each LA, and ensured that these new bodies also covered social care services.

The statutory frameworks were operationalised via a series of guidance documents that set out in detail how policies affecting CHCs and LINKs should be implemented. It was from such guidance, as well as statements contained in other policy and strategy documents that participants gained a sense of the content and intent of legislation.

When it was announced in 2006 that PPI Forums would be replaced by LINKs, the DH published a series of policy documents describing LINKs and their role (2006, 2007, 2008, 2009 and 2010). Generally, LINKs were presented as one of the local mechanisms through which commissioners of health and social care services would engage with patients and members of the public. "A Stronger Local Voice" (2006) emphasised that LINKs were "not there to replace wider involvement" but rather "to promote it" (p.15). Although s. 242 of the NHS Act 2006 already described the legal duty of NHS organisations in terms of involvement, the DH guidance "Real Involvement. Working with people to improve health services" (DH, 2008) clarified that "engagement, consultation and participation are all words that can be used to describe different types of involvement activity" (p.16). However, these three terms were not further defined. Furthermore, it explained that "although not a requirement under s. 242(1B), working in partnership with statutory, third sector and independent providers may help NHS organisations to achieve better outcomes for their involvement activities" (p.37).

It remained the case that local negotiations were paramount in determining the forms of PPI. As discussed in Chapter One, the terminology was ambiguous; also, many

commentators have discussed the vague character of the policy documents and the ambiguities associated with an excess of local flexibility (Cowden & Singh; 2007; Hughes et al., 2009; Martin, 2009). These issues emerged repeatedly in LINK participants' accounts and observed discussions: many respondents desired a stronger operational framework and clearer instructions for how organisations were expected to evolve. As examined in Chapter Five, they also expressed a desire for roles and responsibilities to be defined from above, with particular reference to the relationships between the host organisation and volunteers. These informants argued that stronger regulatory provision from the DH could assist the organisation with minimising friction and negotiating the practicalities of everyday work.

Some participants interpreted this lack of detailed instruction as the symbolic absence of support from the DH for the work of LINKs. As Sheila stated, "I just feel that we're left in limbo". I will further explore the processes and practical decisions involved in 'doing PPI', and the extent to which the ideals of national PPI policies were actually reflected in local practices, in the next chapter. For now, it is sufficient to note that the predominant view in LINKs opposed the idea of local determination (Martin, 2009) as an opportunity to express creativity in fostering bonds with local people. Volunteers reported feeling pressured to develop organisations conforming to their interpretations of legal expectations, particularly after the government announced the introduction of the new LHW. Similarly Welsh officers, especially Blue Sand Hill CHC employees, bemoaned the lack of a detailed 'blueprint' for managing the CHCs and implementing PPI after the 2010 reorganisation.

Overall, the statutory framework in Wales constructed a different context for PPI and CHCs compared to the English regulations. In 2005, the WAG published the strategy document "Designed for Life: Creating world class Health and Social Care for Wales in the 21st Century", wherein CHCs were collectively described as one of the stakeholders in charge of monitoring certain basic aspects of hospital care. CHCs, together with LHBs and Trusts, were part of the framework intended to "empower the community to have its voice heard and heeded" (p.14); in practice, they were expected to devise activities that would provide a mechanism for gathering people's views and "foster a greater sense of collective responsibility" (p.14). This function was consistent with the understanding of CHCs as bodies that would "have an

important advocacy role in ensuring that there is informed discussion in redesigning services as the community's statutory voice for health services" (p.26). In addition, the Beecham Review Report (2006; see Chapter Six), depicted CHCs as bodies with which health care organisations were advised to collaborate regarding "the need to change patterns of services" in order "to enhance citizen focus" (p.75). Here, CHCs were associated with citizen advocacy, a theme that was reaffirmed later in the document. However, it was only with the issuance of the "Guidance for engagement and consultation on changes to health services" (WG, 2011) that CHCs were allocated a central role in sustaining "continuous engagement" (p.1) with the NHS, which was portrayed in opposition to the idea of "perfunctory involvement" (p.1). The guidance was published one year after the restructuring and complemented the increased focus on PPI that both the CHC Regulations 2010 and the then Minister for Health and Social Care assigned to CHCs. However, as noted previously, officers argued repeatedly that they were not provided with clear instructions on how to 'do PPI'. As Dexter stated in interview, "At the moment we are not working to a clear-cut Welsh Assembly agenda. All we're told by the Welsh Assembly is 'you will engage'...the form that engagement takes is not at all clear". I shall return to this point to explore how informants navigated such uncertainty to construct the meanings of PPI in everyday work.

The following section will provide an overview of the roles of key actors involved in the process of making sense of PPI – namely, LINK development workers and CHC PPE officers - as they emerged from policy documents. In doing so, the section will provide further background context about the institutional factors that impinged on the work of PPI.

The role of LINK development workers and CHC PPE officers

Both types of organisation had designated officers to implement PPI policies. Development workers were employed within LINKs in September 2008, a few months after the organisations were officially set up. By contrast, the old Rainbow CHC had employed Joey as a Primary Care and Patient Involvement Officer in 2004 as a consequence of the expanded role of CHCs, while the old Blue CHC did not

have a dedicated officer in charge of ‘doing PPI’. After the 2010 reorganisation, however, all CHCs were meant to appoint PPE² officers. I shall return to this point later in the chapter and in Chapter Nine to explore how this organisational disparity affected Blue Sand Hill CHC officers’ views of PPI.

Interestingly, neither England nor Wales published clear guidance on the roles of the development workers and PPE officers. “A Stronger Local Voice” (2006) described LINKs as “provid[ing] a flexible way for local people and communities to engage with health and social care organisations”. A later passage in the document, though, suggested that LINKs would “analyse...information and decide what to pass on” (p.14). Chapter Seven will examine how some volunteers made practical decisions regarding what information to ‘pass on’ to professionals or to other volunteers.

The DH issued no guidelines covering development workers’ roles, although the guide “Getting ready for LINKs – Planning your Local Involvement Network” (DH, 2007) did explain that during the set-up period, the host organisation was responsible:

for engaging with individuals and organisations in recruiting a diverse and representative group to establish the LINK. In order to get things started, the host will need to focus on outreach and be innovative, to draw in potential participants (p.10).

Further, guidance issued by the NHS Centre for Involvement (Guide No 16, 2009) referred to “community development” as a strategy through which LINKs would “boost local people’s involvement in health and social care, channelling views and experiences from communities to commissioners and providers of services” (p.4). To achieve this, LINKs were advised to “facilitate community development action themselves” and to

collect evidence and local testimonies of the beneficial health effects of community development and use these to champion the case for wider investment in community development by health and care agencies (p.4).

² CHCs used the terms ‘PPI’ and PPE’ interchangeably in the course of the work, although ‘PPE officers’ was the terminology used by Welsh informants to indicate the employee invested with the responsibility for ‘doing PPI’.

The same guidance also provided an “illustrative” list of groups with which LINKs were advised to engage – such as self-advocacy groups, black and minority ethnic groups, homeless networks, and LGBT networks – and proposed several approaches to involvement, including community engagement strategies and using existing communication channels to ensure that people and local groups in the community would be involved.

I suggest that the role of development workers emerged from interpretations of more general guidance and it appeared to develop in ways similar to community development and outreach workers’ practices regarding PPI (in LAs and voluntary organisations respectively).

Similarly, the CHC Regulations 2010 did not make direct reference to the role of PPE officers. Such a position was probably created as a means to comply with the new legislation, which emphasised the need for CHCs to undertake

systematic continuous engagement with the local population and community groups within its district, in order to appropriately represent the public’s view on the operation of the National Health Service within that district (p.18).

Marie, Rainbow and Rural County CHC PPE officer, contended that “in the past the CHC just engaged and that was it at that point of time”; however, she also stated that the new regulations, as well as the Guidance on Engagement and Consultation (2011), represented a significant shift in the approach to PPI and, as a result, they required an officer to be invested with the responsibility of ‘doing PPI’. Ed recounted a meeting that he attended with some nervousness:

All the CHC’s chairs and COs met with the Health Minister last Thursday [July 2010] and she told us some of her ideas, but I’m still not clear, not entirely clear what path I’m supposed to follow, you know? Maybe it’ll become clearer, I don’t know, but I don’t want to go down the path that...they think we shouldn’t be going down [he laughs].

CHC informants, particularly in Blue Sand Hill CHC, acted in an area of perceived uncertainty despite the constraining influence of new duties and legal rules. I shall return to this point in Chapter Seven’s discussion of how officers acted in everyday

working practice. It is relevant to highlight that although statutory frameworks and guidance constructed PPI as an activity whereby actors could make practical decisions in shaping the local applications of policies, participants who were not in positions of power viewed PPI as a duty against which they could be held to account, leading to a preoccupation with the legal framework surrounding PPI. It was necessary for them to arrive at practical understandings of its planning and implementation. In the next section I will therefore discuss whether and how actors attempted to address these definitional ambiguities through various learning processes.

Learning about PPI

Learning is a crucial process in symbolic interactionism. The exemplar study of professional socialisation *Boys in White* (Becker, H.S., Geer, B., Hughes, E.C., & Strauss, A., 1964) described how medical students negotiated their identities and learning tasks and adapted to the medical culture in the process of becoming doctors. During fieldwork, the authors realised that students learnt a great deal about how to approach their studies from interactions, the internalisation of values and the observation of practices. Similarly, volunteers in LINKs and CHCs learned about PPI through interactions, by observing officers and by gradually internalising the symbolic position assigned to PPI within the organisations.

Only Rainbow and Rural County CHC included a general overview on the duty 'to do PPI' and the role of the PPE officer as part of a three full days training session held some months after the establishment of the new bodies. Blue Sand Hill CHC officers usually emphasised the fact that they had to do PPI as a result of the new legal framework, but to my knowledge they did not thoroughly discuss the policy and its implications for the work of the organisation in full council meetings. In both CHCs, informants generally discussed PPI in relation to the appropriate activities that would show compliance with the legal requirements, rather than reasoning on the various meanings that the policy had for them.

In LINKs, informants displayed multiple ways of thinking about how training related to the work of PPI. In Red LINK Sebastian was very keen to arrange training to educate participants about the needs of specific social groups, such as LGBT and BME communities and users of anti-psychotic drugs, and about the implications of belonging to such groups, which were implicitly viewed as hard-to-reach. The aim of such training was to ensure that volunteers became competent in using “the right language”, as Sebastian declared, and could confidently deal with sensitive issues: indeed Sebastian wanted participants, particularly those in the management group, to gain an understanding of the variety of personal needs and circumstances with which the LINK might be confronted. These training events were also open to Greenshire LINK’s volunteers and to local people in general, and were advertised through both LINKs’ newsletters. In addition, Red LINK arranged a Disability Equality Training session following a request from Paul. He reported that participants generally spoke to his carer rather than speaking to him directly, and that people symbolically failed to acknowledge his personhood by not making eye contact with him. He therefore offered to facilitate a training day that would educate participants on how to deal with disabled people in everyday encounters. This was agreed with members of staff, who defined the training as “really important”. In interview, Sebastian reaffirmed the value of these training events as a symbol of the commitment of members to the role:

It’s constant [learning], it has to be on-going, you know – it’s all a big learning curve. How do you expect to go to the community out there if we don’t engage with them, you know if we don’t learn from them, you know, how can we do our job as LINK? We can’t!

He went on to emphasise the value of learning from and about “the community out there”. In essence, he constructed training as a means of connecting with local people to show that they and the organisations spoke “the same language”. Sebastian’s view was strongly supported by the host organisation; for instance, Joyce explained her successful attempt to defuse some volunteers’ opposition to training arrangements:

The feedback from the governance group was that because the contract was coming to an end, we didn’t need to put on any more training and I disagreed with it...But I said, you know, well, that’s...what you want to say, so we took it to the management

group and the management group said no, there should be the opportunity for training all the time [...] We've been a bit proactive, particularly with the LGBT training...somebody...a trainer...will say things, that they could provide training for us, and we said, well, we think it's really important that groups have an understanding...you know, everybody has an understanding about equality and diversity.

As discussed in Chapter Five, Joyce and regular participants often held differing expectations and contrasting views about how to develop the work of LINKs. In some of the meetings I observed, she made a strong case for training sessions as a way to empower volunteers and consequently the organisations as a whole. She viewed herself as acting in the LINK's interests and thus sought to challenge participants' interpretations of current circumstances. For example, several volunteers felt the need to pause LINK activities as a result of the ambiguity surrounding the initial explanations on LHW, as delineated in the White Paper "Equity and Excellence: Liberating the NHS" (DH, 2010). They were anxious that the LINKs might "just disappear", as Michael contended. The host organisation officers and other participants put forward contrasting views and managed to redefine training as a necessity for supporting participants in their role. However, these training events were poorly attended, apart from a meeting on anti-psychotic drugs where local people comprised a good proportion of the audience. Sebastian and other employees were particularly concerned about the absence of representatives from the management group at training days, since these volunteers (who were Chairs of the various LINKs' working groups) exerted considerable influence on decisions about the LINK's working procedures and the allocation of funds for particular activities.

Sebastian perceived the working groups as problematic due to an excessively narrow and mechanistic focus on issues such as mobility, finance and health. As discussed in Chapter Five, he argued that the LINK had to offer a wide range of opportunities to listen to local people and capture their particular concerns. Officers and a few volunteers argued that the LINK had to broaden its knowledge and learn to consider the variety of views and needs that existed within working groups, rather than addressing the same familiar issues. While it is not my intention to dismiss these topics, it is reasonable to argue that other aspects related to health and social care

services may deserve similar attention. For instance, I observed a Red LINK Older People group meeting in which participants were discussing a potential visit to a nursing home in the area. Harriet listed a series of topics to investigate, such as the supply of food and the relationships between members of staff and the elderly. Another participant suggested exploring how gay residents managed their romantic relationships in residential structures, arguing that some people might not come out if they did not consider themselves to be in a safe and non-threatening environment, and that this could be a significant source of emotional distress. Some scholars have contended that there is an “assumption of heterosexuality” (Bauer, Macauliffe, & Nay, 2007, p.65) in residential care and as a result the well-being of gay people deserves particular attention. Harriet looked quite embarrassed and did not comment on the participant’s suggestion, and concluded by saying, “We’ll see nearer the time”. As illustrated in Chapter Five, Harriet was an older woman who interpreted the LINK as a closed organisation, and acted upon this meaning in undertaking the volunteer’s role and evaluating other individuals’ performances. On a number of occasions she expressed the desire ‘to go back to CHCs’ with particular reference to the formal appointment system. Her observed reaction suggested that she did not acknowledge the topic of gay residents’ relationships as a legitimate source of discussion within LINKs, possibly because she was simply embarrassed about exploring sexuality. Also, when Sebastian announced his interest in arranging an LGBT training at a management group meeting that I observed, Harriet contended that it was not necessary to attend an event concerning LGBT people to understand some of the issues that this group may experience. Nevertheless, the episode reported shows how regular participants may limit the array of themes considered within LINKs’ meetings, and how the principle of inclusiveness can be seriously compromised.

Harriet and other participants also declared that they did not need to undergo training sessions ‘to understand people’s needs’. In fact, since several volunteers were mainly orientated towards visits and claimed to have many years of experience in past PPI arrangements and other voluntary organisations, they seemed to imply that they did not require further training as they had the necessary know-how to do the work. However, individuals’ experience, knowledge and skills acquired outside LINKs

were not considered an organisational asset and were not seen to outweigh the potential advantages of conducting monitoring visits. This view was a source of frustration for participants and sometimes exacerbated tension with salaried staff. Joyce was a case in point: she was responsible for ensuring that LINKs complied with DH guidance, but was perceived as imposing an additional and unnecessary task on volunteers. She explained several times that “the LINK is different from what you’ve done in the past” and outlined the extent to which the present roles of LINK volunteers differed from their previous roles:

The participants in the very early days would have liked to just been given a badge, have no training and go off and into wherever they like and...But in the guidance that we were given...The guidance said that ‘enter and view’ is about observation; it’s not inspection – and I think in the previous PPI Forums they did have the opportunity to inspect, but now they don’t! ‘Enter and view’ is about being observant and going and looking to see what is happening in a service, and it might be able to help collect more information.

Joyce’s view conflicted with that of CHC officers. As noted in Chapter Six, old CHC members served as mentors, and their knowledge was highly regarded to the extent that employees attempted to retain some experienced volunteers in forming the new organisations and assisting new people in learning their roles. The two organisations differed substantially in their respective approaches to the necessity of training: in LINKs, only volunteers who expressed an interest in visiting had to attend a formal session and obtain a CRB check; by contrast, all CHC members had to possess cleared CRB checks and were also required to attend a few training sessions at the very start of their mandate. As also mentioned in Chapter Six, in Blue LC Ed reminded volunteers several times that training was paramount in transforming them into legitimate members. Furthermore, these visits were portrayed as crucial tasks of the organisations, and volunteers were formally instructed about them in sessions lasting approximately two hours each, whereby officers or external consultants delivered training on the aims, code of conduct and practical arrangements with NHS staff. In an observed meeting, Esther made a strong case for the symbolic meaning of a CRB check by alluding to – and raising concerns about – a LHB local engagement group whose members were not required to obtain CRB checks. Her comment

suggested that CRB checks ensured that members were far more responsible and reliable than lay people who might be involved in hospital visits, and reinforced the perception of CHC members as uniquely equipped to undertake certain duties. Also Charlotte highlighted the importance of CRB checks for people volunteering in health and social care services.

The next section discusses conceptions of PPI as defined and understood by volunteers and officers. NHS and LA professionals' interpretations will be dealt with in a separate section.

Defining PPI: volunteers' and officers' views

The definitional process is a core aspect of symbolic interactionism in which meanings emerging through negotiations and constant reformulations guide actions and practical decisions. Querying informants regarding their understandings of PPI represented a key step in exploring the social processes involved in constructing meanings of the policy. Generally, I phrased the inquiry as follows: 'How would you define patient and public involvement?' I also posed a complementary question focusing on everyday aspects of the work of PPI – 'What is the work of PPI about?' – in order to enable participants to explain the meaning of the term through practical instances (Hollander & Gordon, 2006) if they struggled with verbalising an abstract concept. In this respect, I drew on the "zero premise" presented by Harris (2006) in his work on the social construction of equality. In his discussion of symbolic interactionism, Harris argued that the statement "the meaning of things is not inherent" (p.374) represents a tacit, yet critical, assumption of Blumer's work (1969) and it emphasises the contingent nature of meaning as emerging from social interactions and actors' interpretive processes (Plummer, 2000).

As mentioned earlier, volunteers' and officers' responses suggested a wide range of understandings of PPI. This was in accordance with the findings of past studies and commentaries on public participation policies that discussed the different meanings of the concept of involvement (see Chapter Two). Participants made sense of PPI in ways that did not necessarily contrast but rather were mutually enriching. In a large

proportion of interviews, PPI was strongly linked to promoting and raising awareness of the mere existence of the organisations and the services they offered; officers described PPI as providing information “to the public domain out there” and “advertis[ing] our services”. In particularly CHCs informants suggested that these tasks could be carried out in several ways: by “standing in a lobby somewhere”, circulating the organisations’ branded materials or, in the case of volunteers, “spread[ing] the word”, by “talking to the neighbour over the fence” or “in the post office”. CHC officers and LINK development workers supplied surgeries, local groups and libraries with their organisations’ leaflets and posters. Simon in Rainbow CHC built a website containing copies of all papers on meetings and reports on monitoring visits. Overall, these activities represented a concerted effort to open a channel of communication with people in the community in order to inform them about a body that could provide support and assistance. This idea of PPI was consistent with several CHC volunteers’ self-understandings of role, which drew on a broad conception of members as local advocates (as illustrated in Chapter Six). However, when describing these activities, interviewees frequently expressed uncertainty regarding “whether they [the public] wanted to use it or not”. This remark mirrored the limited extent of influence that front-line actors perceived to have over ‘the public’ and it also suggested frustration about the lack of control over practical instances of involvement, despite their efforts and hard work. The difficulties encountered in raising awareness and the profile of the organisations were related to the perception of ‘the public’ as uninterested in health and social care issues, as described in Chapter Seven.

Additionally, some volunteers in both LINKs and CHCs reported that the public was unable to understand participation and what it entailed, which reflected the idea that ordinary people lacked the intellectual capacity to comprehend and act upon the policy. This view contributed to sustaining patronising or negative perspectives on people “out there”. As Sheila stated, “The whole of patient and public involvement is that it is difficult because the man in the street doesn’t understand it and doesn’t know what he can do, she can do, to feed into it”. Given that the structures of services and PPI arrangements were complex and difficult to understand even for insiders such as volunteers, officers and professionals, it was believed that “the man

in the street” might face even greater difficulties in grasping the organisational dynamics of and rationales behind services. Charlie stated,

If you go to the poorer areas, they have no idea how society is organised at all. They know that they go to an office somehow and somehow that office looks after their benefits, but they have no idea what’s behind all that and it could just vanish.

Daudelin, Lehoux, Abelson, and Denis (2010) study on science/policy networks in genetics discussed the idea of “epistemic asymmetry” to highlight the intrinsic nature of the knowledge divide between citizens and expert members (see also Fudge & Wolfe, 2007; Learmonth et al., 2009; Martin & Finn, 2011). This concept can also be used to frame volunteers’ attitudes towards members of the general public: as noted in Chapter Seven, volunteers conveyed a sense of separation from other local people, whom they saw as unable to act consistently with established understandings of role and organisational working practices.

Volunteers did not thus limit the use of images of ‘the public’ to make sense of their roles. Rather, my data suggest that also conceptions of PPI were intrinsically related to constructions of ‘the public’ and the difficulties encountered by LINKs and CHCs in establishing contacts with their constituencies (Rowe and Shepherd, 2002). The need “to spread the word” about the organisations at the local level was viewed as the issue of highest priority. Ham (1980) also suggested that members of the public were generally poorly aware of CHCs. Joey, who had a media background and had worked as a radio broadcaster for twelve years, suggested that a PR marketing campaign be created to promote CHCs and that photos could be posted on the organisations’ website so that volunteers could be “recognised in the street”. Sebastian made a similar suggestion for Red LINK’s management group members. Both Joey and Chantal, the Red LINK development worker that replaced Helen when she left, discussed the need to have promotional material in different languages that reflected the ethnic composition of local communities. However, as officers explained, there were no additional resources available to address these concerns. For instance, Ed expressed the view that the CHCs’ funds would only cover core activities:

It's always a matter of resources, Silvia – I mean we don't have a huge budget. If we would have spent a lot of our budget on publicity, we wouldn't actually have anything left to go and visit premises [...] But quite honestly, if you want to try and inform the whole of the population, we'd probably exhaust our whole budget for the year and then in six months' time they'd still be asking you...'I don't know what the CHCs are!' [...] Why do you know about Marks and Spencer? Right, because it's on your television about twenty times a week. They have a commercial and if people found out we're spending half of the budget on advertising, they'd say, 'Well, you should be spending that money on going to visit GP practices', so... You can't win, really.

Ed's construction of PPI as an activity promoting the CHC was consistent with the views of other officers within Blue Sand Hill CHC and of former Blue CHC officers. He also imagined 'the public' as a key constituency that could potentially challenge the CHC's decision on how to invest their financial resources: by imagining the public's counter-argument, Ed highlighted the tension between the need to promote the organisation and the pressure to undertake the statutory duties in a context of limited resources. Ed also suggested that the member's role centred on monitoring visits, which were considered the core task of the organisation (see Chapter Four). This perception may explain why members constructed PPI as a secondary activity in relation to the CHC's traditional work, despite it being regulated by law and highly relevant at the governmental level. Many participants interviewed suggested that 'the public' was the source of difficulties related to PPI, that in effect the capacity of CHCs and LINKs for independent was restricted by a powerful public. Here we may come up against the limits of what negotiations can achieve. This thesis has emphasised the importance of Mead (1934) and Blumer's (1959) ideas about self-interaction as the key process of engaging with one's own self to develop discussion and reflexivity, and this has the potential to help actors to modify their courses of action in the light of new meanings emerging from the interaction process. However, in the CHCs and LINKs studies participants often lacked institutional spaces where they could renegotiate the meanings assigned to 'the public'. Consequently, staff members could not move beyond a view of it as a group of people over which the organisations had virtually no control. As discussed in Chapter Five, particularly the

host organisation officers held alternative perspectives of the public and their perceived lack of interest, but these never significantly challenged the majority view.

In contrast to the CHCs, following the work of its communications group, Red LINK's management group decided to invest a substantial portion of its budget in activities promoting the organisation. Despite its more limited financial and human resources, Greenshire LINK also made a sustained effort to raise awareness by attending local events, taking part in radio programmes and circulating leaflets in local libraries, GP surgeries and community centres. Red LINK even decided to produce a one-minute advertisement that was broadcast on a large screen in a well-known shopping centre in Red City for one week. Two people from the production company set up a mobile information point operating from 9am to 7pm where passers-by could make enquiries about the LINK and leave their contact details. Employed staff encouraged participants to assist the company's personnel in promoting the LINK and approaching passers-by. However, I observed only a very small number of regular participants volunteering to do so, and those who did only volunteered for a few hours during the week.

Additionally, in early 2010 both LINKs decided to invest in a bus advertising campaign, an idea which was promoted by the DH and was pursued by several other LINKs in the country. Volunteers designed a promotional advert that was eventually placed on the lower rear of local buses, and the transport company ensured that the selected ones would cover a wide selection of routes. Although the LINKs were unable to measure the impact of these activities, officers told me (with apparent disappointment) that they did not observe any significant increase in participation following the campaign. Consequently, most participants continued to view PPI as a challenging activity: time-consuming, labour-intensive and posing significant financial challenges, where hard work could not guarantee successful results. Tyler strongly emphasised how the organisational struggles of 'doing PPI' were linked to insufficient financial resources: "The reality is, if you haven't got enough people employed, there's only so much reaching out and engagement that you can actually undertake". This quote anticipates the argument regarding the strong identification of roles and duties that will be developed in Chapter Nine.

Interestingly, a large proportion of participants appeared quite hesitant to criticise the effectiveness of PPI or actual activities related to PPI in professionals' organisations. The intrinsic positive value of PPI conveyed by the DH or the WG was incorporated rather uncritically into volunteers' own constructions. In both organisations, participants acknowledged the rhetorical emphasis placed upon the value of PPI by the statutory frameworks. It is illuminating to highlight a tension between widely accepted assumptions about the value of involvement and an observed difficulty, albeit at varying degrees, in expanding on the notion of PPI. Several participants expressed the hope that their comments regarding PPI "didn't come across too negative[ly]". As Arnstein (1969) stated "the idea of public participation is a little like eating spinach: no one is against it in principle because it is good for you" (p.216); at the conceptual level, public participation is "a revered idea that is vigorously applauded by virtually everyone" (Arnstein, 1969, p.216).

As mentioned previously, most volunteers described PPI at an abstract level in relation to patients' experiences, monitoring the quality of services and proposing improvements, their organisations being informed about service changes, and generally "keep[ing] the NHS in check". Within CHCs, the visiting function was a way to build accountability and a soft means of verifying whether professionals had acted upon the recommendations forwarded by members. Some participants admitted that they were not aware of the expression "Patient Public Involvement" but nevertheless sought to articulate some thoughts on the subject, perhaps as an attempt to save face (Goffman, 1959). For instance, when asked to define PPI, Sally hesitantly stated, "Well, through – through – the title – it is about giving people a voice. That's my perception of it, anyway! If you're saying – if you're using the word 'involvement', that suggests proactivity, doesn't it?" Similarly, Lucy explained, "I don't actually know an awful lot about them [PPI] – I've never had to use them", and connected PPI to the core work of LINKs, which she described as "dealing with the trends and noticing that there are a lot of people saying the same thing". Lucy was actively involved in the mental health and autism local arenas, and in socialising health care professionals to autistic people's needs. Further, Helaine, a development worker from Communities First, also gave a very tentative description of PPI: "I think it's – as I understand it, I might not be very knowledgeable of the issue, as I

understand it, and I guess from a community development perspective”. Intriguingly, Helaine, as well as several other volunteers, struggled to elaborate a conception of PPI despite their involvement in formal roles dedicated to it. The data suggests that many informants offered a pragmatic understanding of involvement that was grounded in everyday practices and experiences, and closely related to the particular social worlds of individuals. This hesitancy in using the term “Patient Public Involvement” also suggests that such a label has more currency in academic and professional circles than in everyday discourses of front-line actors.

Esther provided a telling example of officers’ struggles to understand what PPI entailed and how they could accomplish it. She admitted that she had little idea of whether work in the old Blue CHC could be seen as the type of PPI that the Minister had in mind following reconfiguration. When I interviewed her a few months after the reconfiguration, she complained about the need for clarification from above on the PPE officer’s role and expressed the hope that statutory instructions could ultimately provide an understanding of “what it is all about”. This response suggests that because she was preoccupied with her new legal duties, Esther – like several other officers and volunteers – viewed PPI mainly in legal terms, as work that had to comply with top-down expectations. In particular, Blue Sand Hill CHC officers justified their difficulties with articulating views about PPI by citing past organisational arrangements and the practical struggles that arose from these. As discussed earlier, unlike the old Rainbow CHC the old Blue CHC did not have a designated member of staff responsible for ‘doing PPI’: Blue Sand Hill officers used this point to explain different levels regarding understanding and implementation of PPI.

Further, several participants described the key feature of PPI as the establishment of a formal ‘mechanism’, ‘facility’ or ‘vehicle’ enabling people to become involved and express their views. While some volunteers considered CHCs and LINKs to be the mechanisms through which they were ‘doing involvement’ – Janice explained “it means what we hopefully are doing, getting the patients and the general public involved in the services of the NHS, basically” – not everyone saw the organisations as fulfilling this interface function. Several participants defined PPI as “having an input into health and social care services” in both the commissioning and delivery

stages, but the extent of its influence remained unclear. Some also identified a specific temporal stage for the implementation of PPI: engagement should not occur “when you’ve already started things” but rather in the planning phase, when professionals may make enquiries along the lines of “What can we do about the service?” It was argued that people should have the opportunity to shape the process of involvement during its early stages rather than participation being introduced towards the end of a process, when professionals have already made key decisions and involvement might consist in a tick-box exercise. This view echoes Harrison and Mort’s (1998) suggestion that PPI is a means “by which the decisions and activities of NHS and social care agencies can be legitimated” (p.67).

In particular, I suggest that volunteers and officers, with some exceptions in LINKs, adopted conceptions of PPI closely related to their perceived roles and in effect privileged the core work of the organisations over other activities. In the CHCs, members were pushed towards enacting roles in ways that aligned with officers’ expectations of what they should be doing (although we have seen how a few newly appointed volunteers actively resisted this role definition). Within LINKs, role construction was more problematic: the DH’s idea of inclusiveness seemed to be challenged by experienced volunteers and their well-established assumptions about roles and patterns of working practices. In fact, I found that participants with substantial experience in PPI Forums and the old English CHCs seemed to hold perspectives similar to those of volunteers in Wales and tended to focus predominantly on the internal activities of working groups. Particularly Joyce and few other volunteers tried to negotiate PPI as an integral part of the organisations’ work. This minority emphasised the need to develop training sessions in order to ensure that involved stakeholders explored and understood the social richness of people. As will be shown in Chapter Nine, such conceptions of PPI raised questions about its relationship to the core work of the organisations and challenged well-established working practices. Images of ‘the public’ as presented in Chapter Five also contributed to shaping conceptions of PPI as a topic that challenged the organisation’s ability to deal with the problem of the inherently uninterested nature of the people they served.

The following section illustrates how NHS and LA professionals discussed conceptions of PPI and the extent to which these corresponded to or differed from conceptions of PPI emerging within CHCs and LINKs.

Professionals' views of PPI

The NHS and LA professionals whose views are discussed in this section were regularly involved in the work of LINKs and CHCs as representatives of their own organisations, and provided fairly consistent accounts of what PPI involved. Charlotte, Leigh and Fiona, who were PPI Managers for an English provider and two Welsh LHBs respectively, emphasised patients' interactions with health services as "the operational side of involvement" and as a way "to find out about patients' experiences". LINKs and CHCs were among the local mechanisms professionals could rely on in order to access local views on services – thus supporting professionals in 'doing PPI' and, like Charlotte explained, providing "a shortcut" for the NHS, which was described as a "busy and very stretched organisation". Professionals generally suggested that patients or users of health services were the target group for PPI and that 'the public' was the target audience for public consultations; these consultations were viewed as fora to provide information on changes and the development of services and to allow professionals to hear from involved people. As highlighted in Chapter Seven, identification with patients was relatively straightforward and may have been fostered by the titles of some NHS operational units. For instance, Charlotte, Leigh and Fiona were based within either the Patient Experience Unit or two Directorates of Nursing. All these departments were particularly keen to gather and explore patients' views and experiences of the services they used. The possible influence of these departmental labels on professionals' construction of PPI may be an unintended consequence of organisational decisions. Integrating PPI within a nursing directorate, where patient-professional interaction is paramount in the delivery of services, may well frame patients and the context of care as the main aspects of the policy.

Like salaried staff and volunteers, professionals associated PPI with the need to raise awareness and promote the organisations locally, and acknowledged the difficulties

related to 'doing PPI'. James, the Greenshires LA monitoring officer for Greenshires LINK, linked the organisation to the nature of the topics discussed as well as to a view of the public as not-interested:

The vast majority of people, it's not something that they're actively interested in until it becomes relevant to their lives. I suppose the challenge for the LINK is to make sure that if you do suddenly become interested in something then it's easy to find out about it and how you can get involved.

However, in contrast to most volunteers, James was philosophical about the absence of interest in becoming involved, and in fact emphasised the need for the LINK to establish itself as a local advocate that people could easily access.

In general, professionals depicted PPI as encompassing a "duty to involve", as Charlotte contended when describing her role:

Well, first thing you are making sure that your organisation fulfils that...kind of legislation, which is very strong, you know, and that patients and the public should be involved in shaping local services – the legislation talks about it, doesn't it? That's the crux of it, really.

Charlotte's statement implicitly portrayed the importance of PPI in relation to its status as a legal requirement and offered an interpretation of her role as ensuring that various professionals in the NHS involved patients and the public. Similarly, Kate, the PPI Manager for Greenshires PCT, viewed her role as "advising and facilitating PPI – so it's advising colleagues both in commissioning and provider services about the groups out there".

Professionals also seemed to view PPI as a dialogue between the NHS and CHCs/LINKs, wherein mutual expectations could form and the parties involved were "honest with each other about what we're actually trying to do", like David argued. Fiona defined this as "a two-way communication"; Kate also emphasised the idea of mutual communication, although she portrayed such communication as a strategy to ensure that "the LINK can't go off on a tangent when it doesn't really see what the organisation [the NHS] can either achieve or perhaps is something they're [professionals] already doing". David indicated that the NHS should ideally inform

patients and the public of the reasons why the organisations made particular decisions in planning and providing certain services. He stated that PPI was “all about empowerment” and suggested that professionals should develop a communication strategy that enabled lay people to feel “they have a voice in the direction of travel, of how things are run”. David also expressed a view similar to Charlotte’s regarding the sphere of influence of professionals in decision-making processes for service development:

Clearly, you can’t please all the people all the time, and therefore there has to be a balanced judgement made, and that’s for the organisation to do it, and that’s all about the organisation communicating that back out to the public.

The data suggest that a certain level of professional control was in place to guide LINKs’ involvement with the NHS, and that professionals held a somewhat patronising view of volunteers’ skills. For professionals, another purpose of communication was to reframe volunteers’ expectations “realistically”, as Charlotte put it, by clarifying what they could and could not do, partly to prevent them from feeling disappointed and disillusioned. Volunteers were expected to understand the rules of participation and the extent to which their work could exert any significant influence.

It is illuminating to note that despite her position, Kate admitted that her knowledge of PPI was rather limited; in fact, she questioned me extensively about my study and was keen to learn about formal PPI arrangements in other health care systems. Although discovering this was bewildering, her account had to be considered in light of the complex structure of NHS bodies. Front-line actors such as Kate had “to get on with the job”, like she confessed, in broad organisational contexts where the operational demands of their jobs took priority over theoretical understanding. As a result, professionals may have concentrated on developing practical knowledge regarding PPI rather than exploring theoretical understandings of the concept.

The implications of these views, and how they guided professionals in negotiating the context of PPI and relationships with CHCs and LINKs, are examined in detail in Chapter Nine.

Conclusion

This chapter has discussed the legal frameworks affecting PPI in relation to CHCs and LINKs as set out in legislation, guidance and policy documents. It has also provided a description of how volunteers learnt about PPI and how officers supported training events as tools to legitimate volunteers' participation, prepare them for monitoring visits and, in the case of LINKs, increase their competence in dealing with social diversity. Interviews revealed that participants held different conceptions of PPI; however, these conceptions were not necessarily conflicting or mutually exclusive, but rather encompassed a range of concerns from providing local people with information on health and social care services to raising awareness about CHCs and LINKs. Participants understood PPI as a way to promote and advertise the services of CHCs and LINKs, and as a mechanism to gather information from local people while establishing communication between professionals and individuals.

NHS professionals emphasised the need to ensure that individuals were informed about services and changes. At the same time, some professionals believed that their colleagues were best suited to making strategic decisions and that public involvement should come at a later stage, once "a lot of the thinking has already been done", like Charlotte declared. Some volunteers also argued that the information they gathered should inform professionals' work and that they should be involved in the decision-making processes; this last point was mentioned with varying references to the extent of volunteers' influence and how this could be manifested. Overall, CHCs and LINKs constructed similar understandings of PPI related to the need to raise awareness about the organisations and their associated tasks, and provide local people with opportunities to express their views on the services and the issues that they experienced.

We have seen how only some volunteers identified LINKs and CHCs as the bodies through which expressed views could be heard; other volunteers mentioned a mechanism for involvement but did not connect this to the role of the organisations. Several informants' perspectives on PPI were also shaped by practical difficulties experienced in attempts to increase local participation in view of scarce financial and human resources and, most importantly, by negative images of 'the public' that

undermined the organisations' efforts to expand participation. Importantly, LINKs differed from CHCs in terms of the emphasis that salaried staff and a few volunteers placed on the need to develop a training programme that raised participants' awareness of social diversity and equality issues. In LINKs, Joyce and a few key participants shaped organisational expectations of involved stakeholders by promoting training sessions that encouraged embracing a wider range of needs and social contexts.

With regard to the English top-down policy of choice, which was related to a consumerist conceptualisation of the individual in health care services (Greener, 2003), there was no evidence that involved stakeholders in LINKs were clamouring for choice of this kind at the grassroots level. This observation substantiates Tritter's (2009) remark that "there is little apparent pressure from citizens for increased choice" (p.283).

The findings of this chapter reflect the complexity of PPI as perceived by front-line actors in a social context of active negotiation of roles and relationships. Crucially, there was a general sense that PPI was something that they had to do in their daily work, albeit within constraints dictated by organisational arrangements and statutory frameworks. In the next chapter I explore how officers, volunteers and various NHS and LA professionals made sense of the constraining influence of duties and frameworks of rules, and how they negotiated PPI by making practical decisions in their daily work.

CHAPTER NINE

'DOING PPI' AND SHAPING POLICY

We've had a couple of areas where we were saying things which the LHB seemed to not to like but...it's our duty to...articulate these concerns and we will, but really, I don't want to be in the position where we are at loggerheads with the health board, I want us to work closely with the health board, we require to work closely with the health board and lay with us and I think that's the way we should work. So I'll do my damned best to ensure we work collaboratively and closely rather than against each other¹.

Introduction

This chapter examines and clarifies the extent of differences in operative policies and working practices of CHCs and LINKs within the social and legal contexts outlined in the preceding chapter. It discusses how understandings of roles, relationships in the local arenas, images of the public and understandings of PPI (see Chapter Five, Six, Seven and Eight) affected the local planning and implementation of the organisations' activities.

The account which follows is structured into several sections. First, I will explore how PPE officers and development workers negotiated their role in the course of the work within certain institutional constraints, and how their practical decisions shaped the meanings in use of PPI within the organisations. I will then discuss how the volunteer's role in both LINKs and CHCs was constructed through everyday interaction with salaried staff. Volunteers had constructed informal understandings of what their role entailed, including listening to and informing people in their own local communities by combining their personal lives with their volunteering commitments. However, this sat alongside a formal volunteer role largely shaped by officers, which defined the volunteers as an asset in implementing PPI by supporting

¹ Quotation from interview with Dexter, the first CO of Rainbow and Rural County CHC.

officers in their work with local people. This view of the volunteer's role reflected a legally focused construction of PPI in both countries, wherein actors were concerned to show compliance with statutory duties and guidance. Further, I will analyse how LINKs and CHCs interacted with NHS professionals in relation to PPI and how they constructed the meaning of their mutual relationships in everyday practice, and will show how volunteers maintained 'good relationships' with professionals involved. In a separate section, I will briefly present the key aspects related to LINKs' interactions with LA officers, and will also examine how CHCs dealt with LAs within a legal framework that excluded social care from the CHCs' remit. Lastly, I will introduce the concept of juridification and will show how it is particularly suited to illuminate how actors made sense of top-down messages when constructing operative definitions of PPI.

'Doing PPI': everyday work of officers within LINKs and CHCs

In the early days of LINKs, the role of development workers was largely administrative and entailed supporting volunteers in developing a sense of direction for the organisations. In their daily work, they assisted working groups with arranging meetings, contacting participants, booking meeting rooms, preparing agendas and ensuring that volunteers were provided with all relevant papers. In interview, Helen recounted:

When I first started, it was very much about supporting the working groups to set up and raising awareness of the LINK, so there were two parts of my job, really [...] A lot of it was very administrative, booking meeting rooms with the support of [the administrator], but both of us doing that together, trying to phone around and find out when people are free to come to meetings [...] At first it was very much about raising awareness and trying to encourage more people to get involved in Red LINK. I suppose that was for the first six months [...] And then after that it became a bit more focused around very specific engagement activities.

Helen described a scenario wherein the host organisation complied with DH expectations for her role. However (as noted in Chapter Five) both Helen and Beth

were also expected to facilitate working groups' meetings: all employees agreed that volunteers expressed the need to be assisted by one officer in each meeting. This aspect of the role was very time-consuming and seemed to affect particularly Greenshire LINK, where Beth was the only full-time employee, Rachel was a part-time administrator and Joyce was employed part-time by Greenshire LINK and Red LINK. This was less of an issue in Red LINK, which had two additional full-time employees (a research officer and a communications and publicity officer). Beth expressed mixed feelings about the need to manage several tasks at once:

Then the other thing that takes up probably more office time than anything else is supporting the working groups, so I support the health services group, the mental health group, choice and control, social care group and the communications group and we're starting the learning difficulties group in July as well [...] That's quite a lot of work in itself. The administration of these groups is probably the bit of my job that...it's drier and I'm not so keen on, but that is about the development of the LINK.

I spend quite a lot of time with some chairs supporting them just to chair the working groups, and very little time with others or [a] different kind of support...I mean like with Luke who chairs the health services group, he's incredibly capable and doesn't need much more from me other than to make sure everything's set up right for the meeting or the information's there, the agenda is done and you know we have discussion about that so...it's still a reasonable amount of work but that's as much as he needs. Then the choice and control group is chaired by Kirsty who's really a lovely woman, but she needs quite a lot of one-to-one sort of...almost personal support to chair that group as well, so it's a very different thing to how I would support Luke, but that's probably another part of the role of supporting the chairs.

Although Beth was employed as the development worker, her role constantly competed with other activities that reproduced the work of the LINK at the expense of engagement. For instance, Kirsty was a regular participant in Greenshire LINK who was visually impaired and had restricted mobility, and whom I frequently observed struggling to articulate her ideas. In practice, Beth chaired the choice and control group meetings that I observed, with Kirsty occasionally making comments. By introducing Kirsty as 'a really lovely woman', Beth tempered what seemed to be

subtle criticism of the volunteer, perhaps to emphasise her professional neutrality. In order to reduce the amount of time dedicated to ‘drier’ tasks and relieve her of some of this routine work, Beth suggested that the administrator, Rachel, facilitated one working group.

Similarly, Marie contended that in practice she could not focus solely on PPI because “CHCs have to look at the statutory side [and] primary care role as well”. Monitoring visits and ‘the primary care side’ were seen to constitute the core of CHCs’ work, and were largely prioritised over all other tasks as a result. As in Blue Sand Hill CHC, PPI had to be seen to be addressed within everyday work of the organisation. Additionally, in Blue Sand Hill CHC, Esther struggled to adjust to her new role as PPE officer, partly because old volunteers could not disassociate her current role from her old role of office manager. She recounted:

The members don't really see me as a PPE role yet as such, I don't think. I think they're very much on... 'Esther will answer that one', 'Esther will answer that one', so it's everything and anything. I'm still getting phone calls...Yesterday I was at the induction day to cover [a] monitoring role, which isn't part of my role [as PPE officer], but because the administrator had left and Kelly is new to the position, I'm taking on that role as well and now I'm...training Kelly to do the monitoring – so of course they see me there then as that and I think, you know, I'm here just to pass her job on, so once that goes maybe they'll start to see me in a different view as well then, you know?

Like Beth, Esther also had to support the CHC’s core activities by using some of her PPI time. She struggled to construct a new identity due to a perceived lack of institutional clarity regarding her role (as discussed in Chapter Six). Additionally old members sustained a strong sense of continuity between the old CHC and the new organisation, which left Esther in an ambiguous position. Further, she explained to me privately that she did not enjoy the PPE officer role because “if you have chosen it, it’s fine, but if you’re told that you have to do it...I miss my old job!” This perceived imposition negatively shaped her approach to her role. PPI was generally perceived as having been suddenly imposed upon the CHCs by a new statutory framework created by the then Minister for Health and Social Services. Compliance

with the legal requirements became a high priority, which may have led the majority of actors to focus on the legal dimensions of PPI. In a later section of the chapter, I will discuss how the concept of juridification can illuminate informants' working interpretations of PPI.

Overall, both development workers and PPE officers viewed themselves as responsible for establishing contacts with local groups and informing them about the organisations' existence and remits. Raising awareness of LINKs and CHCs represented a significant part of their work, which might explain why several volunteers suggested that PPI was mainly related to promoting the organisations. Once again, meanings and actions were mutually reinforcing; Beth's description of how she 'did PPI' also exemplified PPE officers' perspectives:

The biggest part of my role is...talking to voluntary groups and also doing more sort of engagement and interactive work with different groups and find[ing] out what their issues are, so I've done everything from very short...half an hour 'tell me what your issues are' sessions, with, for example, the fibromyalgic support group to the event that we did with people with learning difficulties [...] It's very difficult. I think we accessed a very large majority of the community or voluntary groups in Greenshire or the groups that are out there that would have a particular interest in health and social care. I think there are still quite a few groups we haven't accessed, but I think we've done a pretty good job in going to most of them.

Some Greenshire LINK volunteers expressed very positive views of Beth's work because she exhibited expert knowledge of the local area and seemed attuned to local groups' working practices. In a similar vein, Chantal suggested that engagement activities would produce evidence that was "not just about stats", but was also based on "sort of anecdotal stories that are actually quite important" – thereby implying that the LINK provided an arena for individuals to discuss issues on their own terms. For some time after the establishment of the organisation, LINK officers valued anecdotal stories as a source of evidence. However professionals expected volunteers to challenge their work by offering detailed evidence of the issues reported. Crucially, Helen described how she shifted her perspective as a result of professionals' and some volunteers' comments on the presentation of her work:

I think first I was very much taking on anecdotal comments from people. I think the feedback I've had from our [regular] participants and also from NHS Red City and Red City Council – they're looking for more sort of concrete examples. So before it might have been like, 'Oh, I don't like the – I don't know'... 'I waited too long at the emergency department at the hospital', and now I've been asked to actually find out when that was, what day of the week it was, so I think I've learnt to just try and ask as many questions as possible about why something might happen.

Joyce also modified her view on what constituted solid evidence after interacting with professionals and interpreting their expectations. At a Chinese group meeting that I observed (one of the working groups of Greenshire LINK), Joyce made a strong case for the need for detailed descriptions evidencing the issues that Chinese people wanted to report. She imposed the “rule of evidence” (Barber, 1966, cited in Paap and Hanson, 1982, p.420) to substantiate her claim, explaining that when she reported an issue to the PCT, they requested further details.

The institutional factors impinging on PPI work as presented in Chapter Eight suggest that CHC officers were worried that their planning and implementation of PPI activities would not conform to top-down expectations. Officers also expressed concern regarding their ability to comply fully with the CHC's statutory duties due to the impact of the restructuring on working practices (see Chapter Six). COs and Deputy COs reframed their responsibilities in light of the new emphasis placed upon PPI, and found their workloads increasing as a result. Blue Sand Hill CHC suddenly had three officers committed to ‘doing PPI’ to varying degrees. These pressures shaped employees’ practical decisions on how to devise plans that conformed to perceived top-down expectations. As Esther stated:

We've got a PPE strategy, which we have so many aims that we're looking for, so every time I'm doing something I can put it forward as objective and, you know, to show that we're working. I've got a file as well to show the evidence so at the end of the year if anyone wants to see what we've been doing, which we've been asked now...The Director of the Board is putting together a file to give to the Minister to show what the CHCs have done and okay, ours is not gonna be, you know, as good as Rainbow because Rainbow have been doing PPE for longer, but at least we can

show that we are engaging with people...Or at least we meet with the people that we can then try to engage with further on down the line.

A work plan that included aims, objectives and an evidence-based file may have been a formalised way for officers to show that they were actually doing. Joey, with his large expertise in PPI, represented the standard against which Esther and Ed constantly constructed their capacity to 'do PPI': they continuously emphasised that their work could not be compared to that of the neighbouring CHC. As a result, Blue Sand Hill CHC presented its approach to PPI in guarded terms, which acknowledged its lack of extensive experience. Officers expressed the hope that the Minister would take this into account and be sympathetic when reviewing the PPI work of the CHC. Ed argued that "the three CHCs in this area which make up Blue Sand Hill now didn't have a PPI officer" and that "we have nothing here so we have to start from zero", whereas in the adjacent area Joey had "done a tremendous amount of work already and has programmes up and running". This lack of knowledge and the perceived ambiguity of ministerial guidance were a source of "sleepless nights" for Ed, who hoped that "things don't go badly wrong":

The Minister wants us to meet the hard-to-reach but...I haven't got anything in writing which says...What do I mean by the hard to reach [...] So I don't know where we're supposed to start and that's what I'm anxious about. I'm not clear where we should start our PPI priorities.

Ed's view echoed the difficulties expressed by the participants in Rowe and Shepherd's (2002) study in understanding involvement, and how the work should be done. In CHCs, officers' preoccupations were also rooted in the need to provide evidence for the organisations' 2012 review. As a result, officers sought to construct operational definitions of PPI that complied with their top-down messages.

In the English context, Red LINK development workers acted within certain constraints as constructed by the LA. As shown in Chapter Seven, Red City Council imposed guidance on their LINK that specified broad categories of people that they had to engage with.

But even taking account of these external constraints, both organisations acted in an area of uncertainty wherein participants needed to make practical decisions about how 'to do PPI'. In LINKs, opportunities and informal relations were fundamental aspects of the unstructured work of the development officers. Beth explained that her engagement work was "strategic, in that I've been trying to target community and voluntary groups who have a particular stakeholder in health and social care and communities who don't get much of a voice". Such groups involved gypsies and travellers' communities, people with learning disabilities, young people and prison communities. Likewise, Helen explained that her work was "probably a little ad-hoc" and drew on local workers' knowledge and personal contacts through which she identified people "we haven't done any work with". Both development workers negotiated "spending attached to engagement" with participants, which implied that they selected the opportunities on which to place the most emphasis. These judgements thus shaped the organisations' decisions on which projects to implement locally. PPI work appeared to comprise two stages: the first related to raising awareness and establishing informal relations with local people, and the second extended beyond the concept of seeing people to, for example, engaging with a group by organising a day event. As such, volunteers exerted considerable control over the cost of PPI, which might have affected the establishment of groups or the implementation of initiatives. Prior to that, however, the development workers had already decided on what to report to volunteers. For example, Beth admitted that her discussions with other employees or local colleagues significantly affected her judgment on what "should go through" to the core group. She also noted that "when an issue [was] strategic" or "had a spending attached", she would present it to volunteers and seek their approval before suggesting a financial investment. I shall return to the role of volunteers in 'doing PPI' in the following section.

CHCs took a more structured approach to planning PPI. PPE officers, the Deputy CO and the CO drafted a list of organisations and groups reflecting the Ministerial guidance. Esther methodically structured her work, which she showed at the PPE Committee meetings, and Marie showed me graphs, tables and circles orderly presented on a note book. Informal relationships and local knowledge were also key elements of establishing initial contacts with groups and associations. However, in

striking contrast to LINKs, although CHC officers conveyed a general sense of the considerable costs involved in 'doing PPI', volunteers were not expected to make decisions on the allocation of the budget. Blue Sand Hill CHC officers stated repeatedly that they had to carefully manage money in order to ensure that they could undertake their main tasks, particularly as they had not received additional resources to match their expanded role. It was clear that they tended to spend as little as possible on 'doing PPI'.

Both organisations developed similar methods of reporting on PPI implementation. LINKs' development workers produced reports that described what actions they carried out and with whom, and listed a series of recommendations to pass on to commissioners of services. The reports were included in the management group's meeting papers, and a single item on the agenda would read "engagement reports". As noted by Joyce, the participants included in this group were invested with the responsibility of approving the reports, which were also circulated to a few working groups whose area of interest overlapped with PPI, such as Red LINK's communication and publicity group, the equality and diversity group, and Greenshire LINK's governance group. The symbolic position of PPI as an item that was briefly dealt with as part of a long agenda probably contributed to its perception as a peripheral activity for which officers – rather than the organisations as a whole – were responsible.

In CHCs, PPE officers produced an 'activity list' accounting for their work. Rainbow CHC usually included it in the last section of its council papers, following a considerable quantity of minutes, visit reports, and written communications between NHS professionals and CHC officers. During my observations, this list was mentioned in the last few minutes of (mainly evening) meetings, when the chair and officers briefly praised the hard work evidenced by the list – once Abi said that "from the activity list we can see that our officers are always very busy and work hard". The CO would then suggest contacting the office to acquire more detailed information on the activities undertaken. In Blue Sand Hill CHC, Esther made similar comments – "this meeting went down very well" – and usually clarified that other tasks within the organisation prevented her from doing "as much as I would have liked"; she found it difficult to rebalance the organisations' perceived priorities

by altering the established structure of organisational meanings. At no point did I observe volunteers undertaking further investigation of the activity list.

The role of volunteers in 'doing PPI' emerged from the organisational interactions and understandings of roles that were shaped by how PPE officers and development workers viewed their own roles and acted in relation to PPI. In this respect, I observed significant differences between CHCs and LINKs, and between individual CHCs' decision-making processes regarding working practices.

'Doing PPI': the role of volunteers

Across the organisations, the roles of development workers and PPE officers were strongly identified with the duty to 'do PPI'. LINK participants explained, "We do try to work with other people but that's more [the development worker's] role", and added, "You would have to ask her about that [PPI] because she's the development worker". Others expressed the belief that "Helen will engage people" or that the "best example" of PPI could be seen "through the development officer". Such quotes are consistent with CHCs volunteers' comments after the reconfiguration regarding their organisations' PPE officers. Similarly, Fudge et al. (2008) found that the implementation of involvement was closely aligned to the role of the dedicated officer in a programme aimed to improve the quality of stroke services.

Nevertheless, volunteers were expected to varying degrees to support officers with PPI. As my fieldwork progressed, it became apparent that the nature of the assistance expected was twofold. Firstly, observed discussions in both organisations revealed a strong belief that volunteers could 'do PPI' simply by "listening to what people are saying" in their capacity as "members of their own communities". Secondly, volunteers were expected to promote various local meetings and initiatives. In essence, this informal role was a combination of volunteers' status as individuals living in a community and the responsibility of being CHC members. As both CHCs' officers often contended, "CHC members are the eyes and ears of the community". Danielle argued that members should be "ambassadors for the CHC" by promoting the organisation and assisting ordinary people in interacting with health services.

LINK volunteers constructed the informal character of their role in similar ways, as Andy exemplified in interview:

As individuals I think we've all got a responsibility to represent LINKs in our daily lives, you know – I belong to a number of organisations and not pressure groups and not committed with the health service...but odd clubs and things to do like photography, and I belong to a local church and I have been invited on a number of occasions to give talks on the health service [...] I can't deal with complaint but I point them in the direction that they should go to, and above all keeping an enthusiasm for the health service and its local contact. And I think the LINKs' members would involve...You mentioned public involvement...would involve the public in that sort of way, but not, and I stress not, to stand outside of the supermarket giving out leaflets [he chuckles] for 'come and join this setup'!

Here Andy highlights the distinction between the informal aspect of his role and what he perceived as an “obsession” with involving local people. In the former capacity he could listen to people involved in his social life, although he strongly opposed the idea of widening participation in LINKs through approaching ‘the public’ in spaces such as supermarkets². Such places were not suitable to engage with individuals with appropriate attributes, as ‘the public’ was by definition unable to adhere to certain codes of conduct and participate meaningfully. Volunteers’ informal role in PPI was purposefully aimed at individuals and groups from their social networks, which likely sustained the knowledge divide between ‘the public’ and other social worlds. As illustrated in Chapter Five, active volunteers symbolically recognised and promoted the involvement of those new participants who displayed characteristics fitting with their conception of role. This informal role also entailed an expectation that volunteers would strongly identify with their organisations, as if they were always “wearing the CHC/LINK hat”. Joey discussed this point in interview:

Membership need to be out there talking to their local networks. PPE isn't only doing the hard-to-reach groups or the deaf and blind groups or whoever [...] We've actually got one member who is a secretary of the rugby club, for example, in Rural

² I believe he was referring to the trolley dash competition that Sebastian arranged with a popular supermarket chain (see Chapter Seven).

County and he picked up the phone and said to me 'I don't really know what I'm doing on the CHC. My organisation doesn't have a health remit: why am I here?' I said, 'How often are you in your club house? After a game, which is full of people, and somebody somewhere talks about the health services over a pint or a drink and said they've been to the GPs and had to wait for three days...That's the engagement that you can be having, saying 'I'm a member of the CHC, I'll tell you what we do and can you explain to me what your problems are', and that's local engagement so members have got that work to do.

This empirical instance of how Joey negotiated volunteers' informal PPI role supported limited involvement for volunteers and suggested an arena for practical decision-making on PPI from which members were excluded: I shall return to this second point later in the chapter. Joey also reminded the volunteer in his example that being a CHC member was a daily duty which entailed acting as a local ambassador and advocate. One could argue that the emphasis on the individual responsibility to contribute to one's own community transformed a volunteering role into a normative expectation. I frequently observed volunteers in both CHCs and LINKs carrying out this informal role by recounting stories from neighbours, relatives and friends regarding health services. In some cases, volunteers told me informally that they contacted personally local health professionals to enquire about access and availability of services on behalf of other people. Interestingly, in Wales volunteers reported that they introduced themselves as CHC members when contacting professionals, as if that status conferred legitimacy and approval upon their actions. However, what information volunteers passed on depended on their judgements about what was important, so that there was a considerable degree of subjectivity about whether concerns expressed by third parties were dismissed or pursued in the CHC. I shall examine later how some LINKs' volunteers constructed ad-hoc criteria to make practical decisions on what information to pass on to professionals. The public's perceived lack of capacity, and the importance of sustaining good relations with the NHS, probably justified volunteers' decisions to renegotiate certain issues with peers and apply personal judgement. Sheila discussed her gate-keeping role within Red LINK in interview:

Well, it's getting the views of the people who actually use the service [...] Having the opportunity to discuss with others whether their concerns are valid, whether they somehow misconstrue, you know, and that's the whole point of going out to these meetings in the Trust – that you get to know how things work [...] A lot of things on the issues and concerns list that come through [in the LINK], I haven't necessarily made a point of taking them forward to the Trusts but I might bring them up in discussions and that sort of thing; particularly the patients' experience group is a good place to bring those up [...] No, it all happens somehow, even if it doesn't sort of look as though it is or it's not on paper or something like that.

Sheila usually attended PCT Board meetings because they provided useful background information for understanding the operational contexts of professionals – a view that was also expressed by some CHC members. Developing such an understanding made it easier for volunteers to forward realistic requests for involvement and realise the extent of influence upon professionals' work. Also, the patients' experience group seemed a more appropriate institutional space to report issues and concerns than the PCT Board Meetings, which were probably seen more as arenas for professionals' discussions. By acknowledging organisational constraints and practical difficulties that professionals may have been required to confront in their daily work, participants could renegotiate their expectations and act as people with a grasp of NHS dynamics. Harriet contended that when speaking to “other groups that [I] belong to outside the LINK”, she would listen to their issues, “ask them a few questions” and “bring back” those answers that she deemed “worthy” to be brought back. Likewise, Daniel stated that volunteers “should use [their] judgement based on feedback from people” because “not everything, every criticism about the NHS is right”, and added that “a small proportion of people...just like to moan and complain”.

Interestingly, volunteers' claims were in stark contrast to the assertion in the DH guidance that “everyone's views matter”. In practice, the judgements of volunteers seemed to ‘matter’ more than those of ordinary people. This may have been motivated by the need to conform to professionals' standards with regard to the expected quality of contributions and to demonstrate to the NHS that the organisations were careful in assessing requests and concerns from ordinary people.

These internal processes of evaluation and renegotiation also represented an attempt to sympathise with professionals' overwhelming workload and were crucial in constructing relationships with professionals, which will be examined in greater depth in the following section. I attended a CHC monitoring visit in a midwifery clinic where Janice, the team leader, received a last-minute notification from the office about a complaint regarding the general cleanliness of the neo-natal unit³. Janice briefed the whole team on this incident before meeting the NHS staff. During the visit, however, she did not mention the individual complaint, but instead generally questioned professionals about the amount of complaints received. In response, the NHS Manager emphasised the complimentary feedback received from patients, and proudly showed us a notice board near the reception area where all the cards received from patients expressing gratitude and appreciation were pinned. I questioned Janice after the visit; my field notes reconstructing our conversation are below:

I stayed with Janice and we walked very slowly because of her mobility problems. I thought that was my opportunity to ask, 'Why didn't you mention explicitly about the complaint you got?' She said, 'She [the professional responsible for leading us through the visit] knew we knew. She said it wasn't her area – but I mean, she's a senior midwife, isn't she?' I confirmed she was the Midwifery Manager, and Janice commented, 'Yeah, exactly, I mean –' and did not complete her statement. Then she added that she would report it to Joey and see whether they could have an unannounced visit 'even though they [the CHC] might not agree'. Then she concluded, 'Well, this area is part of the HPE visits anyway'.

Janice's strategy aimed to minimise conflict and contribute to an image of the CHC that worked collaboratively with the NHS. I observed her while she reported the whole story to Joey, who looked quite frustrated when she emphasised that the professionals did not mention the complaint received. The complainant's voice might have been lost in the organisational process of balancing advocacy against the need for good collegial relationships.

³ This visit took place approximately one month before the CHC was expected to undertake HPE monitoring visits.

In addition to the informal aspect of volunteers' role, officers constructed a formal role intended to assist PPE officers and development workers in accomplishing PPI as prescribed by the statutory frameworks. Despite some similarities, officers in CHCs and LINKs adopted different strategies to shape this formal role and enable, or limit, volunteers' participation in 'doing PPI'. CHC officers constructed a narrow definition of the volunteer's role, wherein tasks were mainly related to the organisation's core functions as set out in legislation but were nevertheless regulated by officers' views. Conversely, LINK officers encouraged volunteers to support development workers proactively by providing "directions for engagement".

After the reconfiguration the work of CHC officers focused on training members to carry out monitoring visits and ensuring that volunteers understood their role and the new organisational arrangements. The two CHCs established groups in support of PPI that differed in their aims and the diversity of their composition. Blue Sand Hill CHC established a PPE committee consisting of some members, the PPE officer, the CO, the Deputy CO and Leigh, a representative from the LHB who acted as an intermediary between the CHC and the NHS. There were times in meetings when officers passed on top-down messages mechanically to participants. For instance, I observed a meeting where Esther explained that PPE was the term to use in the Welsh context rather than PPI, since "it was decided by the national committee [the All Wales PPE Forum]". However, in practice informants often used the old language of PPI and PPE interchangeably; volunteers involved in the PPE Committee had many opportunities to make small decisions about what PPE or PPI meant locally. The officers often invited members to modify their proposals, for example, on matters such as the layout of the CHC newsletter and the design of the pop-up banner created to publicise the CHC. Nevertheless, members often took a largely passive stance. At the second meeting I observed, the CO put forward a proposal to the chair that "in terms of details, if members have got something to say, they can get in touch with Esther" and stated that although the committee was performing well, it was "better to keep the number of members low in each of the committees we have". No objections were raised, and the chair accepted the proposal. At the committee meetings, Esther also attempted to recruit volunteers to assist with presentations to local voluntary groups or provide some information about

the CHC at a local event. However, members rarely volunteered for this, and usually fell silent following her requests of, “If any members are interested to go...”.

During my observations it became clear that the PPE committee represented a forum for Esther to report about her activities and to show what she was doing. Ed often reiterated that PPI was “a steep learning curve”, and Esther admitted that when she attended local meetings, “some things just go on top off here” – moving her hand above her head – “but hopefully some will start to go in”; here, she pointed at her ears. When presenting her activities at meetings, she tended to emphasise the quantity of contacts established, probably to demonstrate her commitment “to catch[ing] up”. At full council meetings, she provided only a sketchy account of what PPI work would have involved. Her accounts of engagement with local people reflected her general conception of PPI as promoting and raising awareness about the CHC and the advocacy service. At the time of fieldwork, PPI was built upon the need to comply with the legal framework by providing evidence of ‘doing’.

By contrast, Rainbow and Rural County CHC established a PPE Network consisting of the PPE Officer, the CO, the Deputy CO, two professionals from the NHS, the LA and a few individuals from local voluntary organisations. The aim of the group was to share information about public consultations, changes in services, and local initiatives: as Joey explained to me, “strengthening the relationships with the voluntary sector is a new target for CHCs and we’re trying to fulfil that”. Members were excluded from the PPE Network. Interestingly, volunteers did not raise any objections, which probably reflected the strong sense of trust in officers’ decisions (as illustrated in Chapter Six); nevertheless, a few members to whom I spoke appeared unaware of this network or to have only vague information about it. In a second interview, Joey clarified the rationale behind the choice to exclude members:

We’ve decided to put that [the PPE committee] on hold, the reason being is twofold really. One: the level of membership that we have in the area, with the amount of work that we have to do, the visiting, the monitoring and the scrutiny role; and also obviously the fact that we actually lost a lot of members during the reorganisation so they’re all brand new members, who again are getting used to what their role is as a CHC member. I think throwing a PPE function at them as well may well have been

too much, taking into account all the other groups – and although we're not the largest LHB in Wales, I think it's probably one of the busiest because of the tertiary element, secondary care and also the local services they provide, 'cause it's a major teaching hospital as well for the whole of South Wales. We monitor those services so therefore for members to be signed to the PPE function it'd be difficult.

This extract provides an interesting explanation as to why members were kept at a distance from the organisational PPI arena. Joey constructed PPI as a function and made sense of it against the broader organisational context. The combination of new members that were still in the process of learning the role, the characteristics of the LHB that implied a significant workload for volunteers, and all the statutory duties they had to undertake certainly did not leave much room for learning and doing PPI. By doing so, Joey reinforced a narrow definition of the general role of members related to the organisation's legal duties as set out in legislation (as noted in Chapter Eight) and at the same time shaped a conception of PPI as a peripheral activity detached from the core of the CHC's work. Both Joey and Esther mentioned future plans for members to receive ad-hoc training to involve volunteers in 'doing PPI' in a formal capacity; though, the time scale for these plans was vague and loosely referred to a future point in time when volunteers had settled down. Joey described the formal role that he envisioned for members:

I think sitting in another committee just to discuss things...I can't see the worth of that at the moment. We're using their valuable time to do that 'cause they're unpaid volunteers – as you're aware, I think – by asking, 'Oh, could you come to another meeting to talk about engagement?' I can't see the worth of that, personally [...] I think members could well do PPE on an ad-hoc basis, for example looking to set what they call the speakers' group by training members to go and give presentations, go and give talks on the CHC and our role, but they have to be empowered to do that, they need to be trained to do it.

Not everybody can stand in front of one hundred people, keep them engaged and talk to them and give them information and also being able to answer the questions – 'cause members don't go with the breadth of knowledge that, say, the CHC office staff would, 'cause we're involved in so many different things! The actual member

may have a single view on that which may not be the CHC view [...] 'cause they're independent of thought and mind, they may go off a different tangent and it may not be the tangent we want to go off at that talk [...] So to me that's more valuable than sitting in a room in the office talking about PPE. It's all work for professionals to actually lead it but for members to go off and do that, and I think that's where they can really get the flavour of what's going on locally.

The need to project a consistent front in ways that resembled professional organisations was paramount in negotiating volunteers' access to PPI: members had to learn to fulfil their formal role prior to public exposure. Despite acknowledging, as Ed did, that members could hold differing views and have individual interests, Joey planned to shape the volunteer's role in a way that was deemed appropriate in public arenas. Although Joey, as well as other officers, stated several times that CHCs were members-led organisations, this belief did not apply to PPI, which appeared to be a distinct realm regulated by an informed but top-down division of labour imposed by officers. Additionally, empowering volunteers to acquire a professional competence may have increased the symbolic distance between volunteers and 'the public', and may have linked volunteers to professionals more than to lay people.

While CHC officers controlled volunteers' involvement in PPI by restricting access to certain PPI fora, LINK officers were keen for participants to assist development workers, encouraging them to make suggestions and accompany the development workers to local meetings. Staff in both LINKs created Engagement and Involvement working groups in the early days of their respective organisations. These groups were "sort of steering group[s] for directions on how we can make sure we are reaching out to a wide range of people". Employees argued repeatedly that they were doing work "on behalf of the volunteers", and as seen in Chapter Five, Joyce attempted to balance her input with the principle that "the LINK [was] theirs". The Engagement and Involvement group may therefore have served as a practical attempt to expand volunteers' participation in PPI. Initially, these groups met on a monthly basis and were attended by a few volunteers. Various NHS and LA professionals were invited to give presentations about their specific area of competence. It was explained that Helen participated "once a quarter to show them what I plan to do and then they make comments on it, so I tend to do that or I go along with a project plan".

Symbolically, these groups mitigated development workers' sense of detachment from the volunteers: Helen reported that she felt "a bit more accountable" to participants as a result of attending the groups. Regrettably, it was noted that these groups "never took off". Similarly, Fudge et al. (2008) noted that the patients involved in a programme concerned with the improvement of stroke services did not express particular interest in participating in the user involvement subgroup in contrast with the relative high attendance at meetings discussing training and the provision of information. I attended one meeting where I was the only member of the public present in addition to Joyce, Beth and Gary. As a result, volunteers suggested merging the engagement and involvement groups with other key groups within LINKs. Joyce made sense of the then current situation as follows:

In both LINKs we had a separate engagement group and it hasn't worked! Nobody has really wanted to come forward to support the work of either Helen or Beth which is really, really disappointing [...] But it's almost like two bits to the LINK, you know...They're the bit doing the working task groups, and there's the host doing the engagement, and really the host are doing the engagement because that's what we've been told that we should do, reach out and hear from the people of Red City. But this part of the LINK, the working groups need to value that part, which is why now, you know, we've just sent all the reports of the work through.

LINK volunteers were perceived to be more interested in the core tasks of the organisations; the reports mentioned by Joyce were the written evidence of the development workers' engagement. As with CHC volunteers, dedicated salaried staff were strongly identified with the duty to do PPI, which may have increased the symbolic divide between volunteers and their expected contribution to the policy. However, participants' interpretations may have been affected by the low attendance rate of development workers: Helen did not usually attend the management or core group meetings, and Beth only attended them every three months. This factor did not facilitate the unfolding of relationships and dialogue between staff and volunteers, but probably contributed to the construction of involvement as a separate activity occurring outside LINKs. Although Joyce suggested that Helen be invited to Red LINK's management group meetings, these were regularly held on Tuesdays, which was Helen's day off. Joyce clarified that the meetings would need to be rescheduled

for Helen to be included in the management group. Volunteers did not engage in discussion on this point, and a few volunteers sitting next to me whispered, “it is not possible”. The group fell silent and then moved to the next item on the agenda. After this discussion took place, meetings continued to be regularly held on Tuesdays. Later, Chantal tried to get the LINK to think differently about PPI in a management group meeting, where she prompted participants to make suggestions on engagement and encouraged them to contact her. After her brief statement, volunteers thanked her but did not ask questions. She explained to me that they were “interested in their issues to take forward, which is great, but not necessarily interested in the bigger picture”. To the best of my knowledge, participants never contacted her during the remaining two months of my fieldwork. Chantal endorsed other employees’ view of volunteers as uninterested in a formal role in PPI. Sebastian and some others, who regularly attended the communication group meetings, were keen to participate in the LINK’s engagement activities. However, this did not always happen in practice. For instance, in an observed meeting Michael volunteered to support Helen in her work with Somali women, but Helen and Joyce argued that it was not appropriate for him to join the group, as the women might feel uncomfortable with a man in attendance. On another occasion, Tanya volunteered to attend the mobile information point set up in a shopping centre of Red City (see Chapter Eight) and offered to join the people from the production company in different days during the week. I later discovered, in an observed meeting, that she only attended for a few hours on one day. Furthermore, Gary stated that he was available to assist Beth by attending meetings on her behalf in the evenings, on Sundays or in the daytime; in fact, he attended a meeting on a Sunday afternoon where I was also present. While Gary often claimed that “we’ve got people out there who are very good and very willing to give up their time”, I never observed a meeting where participants volunteered to attend Sunday or evening meetings.

Interestingly, the two LINKs adopted contrasting approaches to creating a space for the discussion about how to promote local involvement following the dissolution of the engagement and involvement groups. The governance group in Red LINK proposed to establish one group dealing with governance, communications, publicity, engagement and involvement, whereas in Greenshire LINK it was suggested that ‘the

bit of engagement' be added to the communications group. Negotiations in Red LINK were relatively straightforward: in a management group meeting volunteers decided that, since "you can't have communication without engagement", like Sebastian explained to me, the new group would focus on these two topics and the governance group would remain independent. In Greenshire LINK the discussion was developed in the governance group amongst some of the most influential volunteers, who were also the most actively committed. An extract from my field notes of the meeting is below:

Item three was about the merger of the engagement and involvement group with the governance group: it was originally proposed that the communication group could merge with the engagement and involvement, but Michael and Luke didn't agree at all. They argued that the communications group didn't have anything to do with engagement. They now had to position Beth's reports on her work: which group should host her? The governance group? Tyler was not happy with this decision. He acknowledged it could be a good idea to reduce the costs of hiring venues but forcefully added, 'You can have your engagement and involvement group after the governance group, when I can leave'. He raised the issue of accountability. He complained that the host organisation did not always report properly about meetings attended on behalf of the LINK. He mentioned the fact that Joyce took part in a council meeting where she had no slot to speak and she didn't feedback on what they discussed during that meeting. Tyler said, 'How can LINK benefit from their attendance if there's no report and there's no slot for them to speak? I don't think that move has been so much clever'. He also said that he went to the North of England to meet other LINKs' reps and that they all have the same problem, which is the issue of engagement. 'Joyce and Beth haven't failed; it's just the way it is everywhere!' Gary then asked, 'So shall we put a slot on engagement and involvement for Beth to report back on her activities?' Luke came in and somewhat summed up the decision to make: 'Well, the purpose of engagement and involvement was to monitor the work done by the staff, so now that activity will be incorporated in the governance group where she can come quarterly?' Everybody agreed that once a quarter Beth would attend the group to report about her work. They all viewed it as a form of accountability to participants.

Beth explained to me that Michael and Luke's reluctance was due to their belief "that there's quite a lot of spend attached to engagement" and that since the governance group monitored the LINK's finance, it would be "more appropriate" for the engagement and governance groups to merge. Ironically, Greenshire LINK was desperate to raise awareness of its existence, and the communication group's volunteers were particularly committed to devising strategies that broadened the number of participants. Further, my observations suggested that the purpose of introducing "a slot on engagement" was twofold. First, the volunteers involved in the above discussion were keen to control resources tightly due to their limited budget; this was a general trend across all groups in Greenshire LINK. Secondly, by doing so, these influential volunteers indirectly made Beth accountable to the group, which pushed the strategy towards "monitor[ing]" her work and "the spending attached to engagement", rather than providing an opportunity for participants to contribute meaningfully. In an interview, Gary described Beth as "a bit remote because she tends to do her own things", although he also expressed great satisfaction with her local knowledge.

Furthermore, the relational difficulties illustrated in Chapter Five significantly informed the discussion reported in the extract above. The argument for greater financial controls on engagement built upon the ideas that PPI was a 'difficult' topic and that LINKs "all have the same problem" across the country, like Tyler explained to me; this chronic and hopeless lack of public interest had to be addressed wisely, albeit with scarce resources. This decision symbolically redefined PPI: Greenshire LINK reduced its engagement and involvement group to a brief "slot" on the same topic. Gary also reported that the presence of Beth at the LINK's meetings "was another way of sort of keeping James [the LA monitoring officer] quiet".

Additionally, in Greenshire LINK, the core group members constantly reminded each other that as their financial resources were extremely limited, they had to be wary of supporting events or activities that could significantly affect the budget. These reminders often drew comparisons with Red LINK's stronger finances. In meetings I observed, various informants often explained that Red LINK was allocated a more substantial budget "because there are more people in Red City", whereas "Greenshire didn't get quite so much money because there are less people". Volunteers also felt

that the budget did not take into account Greenshire's rural areas, which meant "there are wider distances to travel for people to become involved". Some participants reported that a few peers lived in very remote areas, and as such their travel expenses claims affected greatly the organisation's finances. These factors were seen as the primary constraints on the LINK's budget.

Within CHCs, members were equally concerned about financial resources. Unlike LINK volunteers, however, CHC volunteers relied on officers' judgment and decisions on how to allocate the budget. After the reconfiguration, the Executive Committee membership was responsible for monitoring finances; I never observed members objecting to the proposed financial projections. Similarly Blue Sand Hill CHC officers never presented the estimated costs of PPI to the PPE Committee. Members were made aware that PPI was a key theme of the organisation even though CHCs were not assigned additional funding to 'do PPI', but they largely relied on officers to deal with these issues.

I shall now turn to discuss how CHCs, LINKs and professionals negotiated the practicalities of PPI in everyday interactions.

'Doing PPI': negotiations within the NHS and LAs

As demonstrated in previous chapters, professionals conveyed a general sense of their organisations' expectations of volunteers. The establishment of meaningful contributions to professionals' work was one of the key features of these expectations. This section explores how CHCs, LINKs and NHS professionals negotiated and enacted PPI in view of the circumstances outlined throughout this thesis. It is important to note here that LINKs covered social care services – a realm excluded by law from the role of CHCs. However, CHC officers seemed to create markedly different strategies to deal with LAs. I will therefore discuss LINKs' and CHCs' relationships with LAs in a separate section.

Understanding PPI in the NHS

Interestingly, the legal aspects of PPI held a strong symbolic significance for individuals involved in CHCs and LINKs: volunteers expected professionals to create meaningful opportunities for involvement as a result of legislation. In response, PPI Managers pointed out that one of their roles within the NHS was to ensure that professionals conformed to the statutory framework and all the legal duties that that entailed for an organisation, or in other words, to advise NHS professionals on how to fulfil the duties of PPI (as examined in Chapter Eight). However, professionals were not legally bound to act upon ideas, suggestions or reports produced by the organisations, as already discussed by Harrison and Mort (1998); CHCs made an exception in the case of public consultations, wherein the LHB was required to consider the EC's approval or refusal of professionals' proposed changes to health services.

For instance, a document created by Chapman (2012) as a Director of Public Engagement and Communications for NHS North of Tyne listed various negative consequences that may result if the duty to involve is not met, or if individuals and groups are not happy with the decisions taken by professionals. According to this document, a lack of involvement could result in a referral to the Secretary of State through a local body or to a judicial review. The document also refers to "negative media coverage" (p.4) resulting in failure to meet legal requirements and difficulties in sustaining collaborative relationships at the local level. During my fieldwork, though, I never observed volunteers discussing the possibility of making referrals; instead, they attempted to avoid overt conflict and negotiated adjustments, albeit with reluctance, to sustain involvement in professionals' work. In addition, "Involving people and communities: a brief guide to the NHS duties to involve and report on consultation" (DH, 2008) contends that professionals are in a position to decide whether an NHS body may have "good reasons" (p.5) for not complying with the duty to involve; although this guidance does not provide examples of what constitutes "good reasons". In light of the 'epistemic asymmetry' (Daudelin et al., 2010, p.267) between professionals and ordinary people, the former were probably better able to influence the definition of 'good reasons' in relation to the meanings assigned to participation.

CHCs and LINKs developed similar strategies to negotiate and sustain their involvement with the NHS. In LINKs, there was a general feeling that the NHS was reluctant to be monitored by volunteers, and that professionals were suspicious and wary. Sebastian argued that some NHS professionals operated with “that kind of – I suppose – dinosaur attitude that, you know, they know best”. Some volunteers wanted to have a greater say in challenging that mind-set due to a sense of ownership of the services, as these were funded by taxpayers’ money. Daniel explained his perception of professionals’ views on volunteer interaction as follows: “If you’re a manager in the NHS you want to get on and do things, you know and all these people saying, you know, hold on a second...they’re a nuisance!” Several participants reported that the NHS simply wanted ‘to tick the box’ and comply with regulations rather than to engage constructively with local people. Max suggested that NHS organisations viewed PPI purely as a duty – “From the health bodies’ point of view it’s...‘Oh, we have to do this; don’t really want to do it, but...what can we do?’” – and similarly Gary contended that professionals were “just telling you what they intend to do rather than saying, ‘Do you think this is the right thing to do?’ or, even better, ‘What would you like us to do?’”.

Charlotte partially confirmed volunteers’ views of the attitude that professionals displayed regarding their input. She framed professionals’ views within the social and cultural contexts of health services, which she described as “very entrenched”, and stated that professionals operated with the mind-set that “they’ve always done things in this way”. She added that this mind-set was shaped by “a model that was very patronising”, and that although progress had been made, “the idea of having patients commenting and suggesting things, to a lot of services is still quite threatening”. However, it was made clear that volunteers’ involvement was appreciated when it could provide practical benefits for professionals in their everyday work.

Sheila tried to explore the reasons for professionals’ reservations about LINK volunteers undertaking an ‘enter and view’ visit:

I mean it’s been hard work, really, because historically trust like that would be very defensive and they are subjected to lots of inspections from all sorts of people, and

we're just one of them, and we have no qualifications. We're lay people – what do we know? The fact that we might be patients is, you know, not necessarily acknowledged, but, you know, it's been a hard job to demonstrate that we're not there to criticise, we will – I hate the word, the phrase now – critical friend! Oh, it's been overused and overheard so many times, but yes, we are...we were described as reasonable people so I think that's a good thing, so hopefully it will continue.

Rather than renegotiating professionals' perceived assumptions that volunteers could not adequately contribute to services due to their lay status and lack of qualifications, Sheila endorsed professionals' views to a certain extent. She equated the concept of "critical friend[s]" with "reasonable people" who "are not there to criticise". This view may be substantiated by observational data from a Greenshire LINK core group meeting. Gary reported a discussion that took place within a joint meeting between the two LINKs, both of which were planning to undertake an 'enter and view' visit. In his account, Gary subtly accused Sheila of being too soft with professionals, reporting that she had argued that "some of the questions which were going to be addressed to a member of staff in a hospital were too weird", and also insinuated that Sheila was a close friend of this member of staff: "The word friendship wasn't actually mentioned but you know, she said, 'This is a lovely person and very nice and very committed to her work'". From my observations of meetings, Sheila appeared to create and maintain an image of herself as 'reasonable' through compliance with a professional approach to volunteering (Goffman, 1959).

Arthur agreed with Sheila's argument regarding volunteers' lack of qualifications, stating:

If you're thinking about a regime of checking and improving and monitoring, you got to seriously ask: what's the point or what's the added value of a group of people in wandering around a ward?

He was highly critical of how volunteers interpreted the power to visit NHS premises because it did not benefit professionals, but rather satisfied volunteers' desire to do "an exciting and powerful thing". The verb 'wander' might refer not only to volunteers 'getting lost' in the physical space of a hospital, but also symbolically

refer to a perceived lack of direction, logic and coherence in examining services that might be of little benefit to professionals.

Kate offered an insight on how the meaning of an 'enter and view' visit was renegotiated by her colleagues:

The difficulty I found was that providers do not want a group of people coming into their service if they don't have anything specific in mind... You know, they are there but for what purpose?... I suppose it was from my point of view quite... not frustrating, but it took a while to get that message across that, you know, they understood... Providers understand, you know, the reason for it ['enter and view' visit] if there's a need, but just to have a sort of a blanket, you know, coming and looking around when obviously staff are busy and services need to be delivered, it's – yeah, it wasn't possible.

'Enter and view' visits were part of LINKs' statutory powers (The Local Involvement Networks Regulations SI 2008 No 528). These visits were quite popular amongst participants previously involved in CHCs and PPI Forums, where monitoring visits appeared to represent the core of their work. As we have seen, CHC members accorded the same preference to monitoring visits; however, volunteers soon learnt that they were required to provide a reason for the disruption that professionals would face due to an 'enter and view' visit.

Joyce also expressed support for NHS professionals with regard to 'enter and view' visits:

Some participants got really uptight, saying, 'It's no good going on a visit if they're going to sort it out before we get there'. Well, that's great, isn't it, if they know there's a problem and they sort it out before? But oh! It was always like they wanted to catch somebody out!

This perspective constituted another source of conflict between her and volunteers.

As a result, volunteers often expressed frustration and disillusionment when they realised that they had to manage a further layer of negotiation to use one of the organisation's powers. To paraphrase Blumer (1969), legislation erected a

framework for action but was not a determinant of that action. Since professionals expected the organisations to collaborate and engage in joint action (Blumer, 1969), volunteers had to adapt to NHS working practices as interpreted by local professional representatives and negotiate the terms of their involvement. Strategies of self-presentation were thus crucial in interactions with professionals: establishing reasonableness was essential to laying the foundations for future relationships.

Welsh informants expressed mixed views regarding professionals' negotiations about the meanings of PPI. Some of these perspectives were distinctly negative, as expressed by Joey in interview:

The NHS never wanted the CHCs. The NHS, if you look back in any literature – and I am quite sure you do... They wanted the CHCs under their ring; they want to control the CHCs! [...] I think prior to the NHS reconfiguration [when] we had the old officers in post, I would actually say without being...rude...that the relationship between the NHS and Rainbow CHC was strained. It was very tense; it was near breaking point. It has improved gradually since the NHS was reorganised.

However, volunteers' and officers' views on the NHS were not static, but rather fluctuated along a "love-hate continuum", as Danielle put it, where participants moved from one extreme to the other depending on the subject under discussion. In correspondence with some LINK participants' accounts, some CHC members described professionals who attended CHC meetings as "put[ting] themselves on the line" and "very, very brave to come along not knowing what was going to be thrown at them". Some volunteers expressed fairly positive opinions of local professionals and their attitude in interacting with the CHC. Several informants judged the nature of the relationships with the NHS positively based on their observations that professionals attended the CHC meetings, and that this was an opportunity for members to draw attention to problems and make inquiries. My observations confirmed informants' interview accounts of volunteers questioning professionals on their progress in acting upon issues raised by the CHC, or on how they were planning to develop services.

The role of CHCs as critical friends of the NHS offering honest criticism with the goal of improving NHS services was broadly endorsed by volunteers and officers. Joey drew upon a telling metaphor to illustrate the ideal nature of this relationship:

A true friend will come up and say, 'Look, if you wanna go for a night out, you know you've got cabbage in your teeth?' or somebody who actually says, 'Look, don't go out dressed like that – you look awful!' ... That's a true friend, and I think that's the friend we should be.

Differing and even conflicting definitions of how professionals were perceived in involvement emerged from informants' discussions of professionals and the NHS. Relationships between CHCs and the NHS were not framed via fixed meanings, but rather were subject to various interpretations constantly emerging from interactions and situated contexts (Blumer, 1969).

Volunteers understood that their criticism had to be constructive and follow the working practices learnt over time through interactions with officers. Chris, a volunteer, explained, "Criticising the services that they are providing is obviously something that they don't enjoy, but you gotta go about it in a constructive way...not...make it a personal issue". It was a common view in both CHCs and LINKs that professionals did not appreciate volunteers' comments. Volunteers were thus expected to offer constructive observations and, in LINKs, to appear 'reasonable', as Sheila put it, which reflected pragmatic understandings of the volunteer's role (as illustrated in Chapter Four) and the importance of self-presentation in PPI. Some experienced volunteers appeared to create meaningful individual bonds with professionals based on their local reputations, which facilitated relationships between professionals and the LINK as a whole. As described in Chapter Five, the 'open door policy' sometimes attracted people who did not fit the model of the ideal volunteer. These people could in fact compromise and even seriously damage the reasonableness demonstrated by other participants. However, experienced volunteers such as Luke, Sheila, Emma, Harriet and Gary were well-known in the local arenas in light of their long history of involvement with professionals in other organisations, which seemed to reassure symbolically and affect positively relationships with NHS professionals. Luke contended:

My health group always has somebody from NHS Red and NHS Greenshire and one or two people always come, and they take the issues that we raise, take them away and bring us back answers. That's because of the networking – I mean those people I have known for a long time before the LINK came up – so it's a matter of making the best of existing networks; you know, people will come along and think...it's a friendly atmosphere, not a bear pit [he laughs].

Luke suggested that other voluntary organisations or members of the public might fail to provide non-threatening environments. Within other meetings and events, Luke argued that professionals could face individuals who were considered to belong to pressure groups and were labelled as non-constructive or unable to properly interact, or were seen to 'keep asking the same question'. CHCs and LINKs sought to resist such labels by meeting professionals' expectations. In practice, this not only entailed adjusting lines of behaviour, but also the presentation style of ordinary people's comments that LINKs decided to pass on to NHS bodies. For instance, Nadine stated:

One person sending a letter to the LA doesn't really necessarily have much clout, whereas collecting these opinions and putting them in a more commissioner-friendly way and presenting them that way...gives people more say.

Chantal also emphasised that when "volunteers might write a report", that report would often need to be edited so that it would be useful for the commissioners and would "be listened to and...taken on board". Furthermore, Emma strongly emphasised the importance of sharing the same vocabulary and meanings as professionals:

I don't know – maybe that sounds a bit pompous, but if you're talking to people in NHS organisations the same as if you've worked in social care and you're talking social care, if you understand their jargon and you're able to talk their language then they listen to you.

Similarly, Rainbow CHC staff offered volunteers some help "with the language" to write reports about meetings attended or monitoring visits undertaken.

In a public meeting that I observed, aimed to promote both LINKs, a question-and-answer session with NHS managers and LA executives was strictly controlled by a limited set of questions passed on to professionals before the meeting. It was also made clear that attendees would be limited to one follow-up question. The format of the event and the prescriptive nature of the rules imposed by some volunteers from both LINKs and a few officers at the planning meeting resembled a press conference rather than an event open to local people. The following extract is taken from my fieldnotes about the planning meeting:

They all agreed that the public would be able to email the questions to an officer's email address before the event or alternatively they could write questions on Post-it's at the event and put them in a big box placed next to the main entrance of the venue (where there will be a signing list). Also, Nadine suggested that people could write down their questions at the end of the session (if they won't be answered) and they can get their replies by email. Nadine added that "after the meeting we can supply follow-up answers and so on" to the people on the signing list.

In both CHCs and LINKs, it seemed that producing evidence of PPI activities was an essential aspect of the interpretation of the policy, and that it was likewise essential to establish the organisations and individual volunteers in ways that enabled them to sustain involvement with professionals.

Sustaining relationships with the NHS

The above discussion of how professionals and the organisations held differing, and often conflicting, understandings of each other's organisational environment sets the background against which actors made practical decisions on PPI planning and implementation. In particular, volunteers and officers had to make decisions on how to sustain the relationships described in the previous section by negotiating PPI activities and their involvement with professionals in general; they devised strategies – sometimes reluctantly – that avoided souring relations with the NHS. PPI was thus subject to constant negotiations. In interview, Joey described the discretionary nature of PPI as shown through professionals' working practices:

We were told two weeks ago about their plans for the next twelve months, we were told two weeks ago that...they've already put in their board, they're consulting with the CHC on this...They haven't! They realised, at the last meeting we had or the Friday before last, where they said, 'Oh, we haven't consulted with you yet', and it's going to the Board...I sit on the Board; you haven't consulted with us at all. Hence tonight we'll hand them half an hour of our meeting to talk through their plans so they can actually say that they have initially had initial discussions with the CHC, 'cause again they haven't quite learnt the lesson. We've been amenable; we've tried, we've bent, we've made way in our schedule tonight for this meeting to take place so the health board doesn't lose his face when it goes to board.

Joey suggested that some senior professionals had misled the Board by saying that they had consulted – in line with the legislation – when they had not. Nevertheless, he had altered the agenda so that the Deputy CE could present the LHB programme to the whole council at the meeting. In this way, the CHC cooperated to avoid embarrassment and discredit for the LHB, and also to maintain the LHB sense of face as a professional body committed to the legal framework of involvement (Goffman, 1959; 1967/2005). Before the members arrived, the officers, chair and vice chair of the CHC discussed this in a very low voice; despite sitting relatively close to them, I could not hear a single word. This occurrence suggested that officers managed criticism and certain issues of concern only with the chair and vice-chair. The alteration of the agenda also caused some internal tensions. One of the advocates, Lexi, was tasked with opening the meeting in order to present the role of the advocacy service. Lexi, who sat next to me, repeated several times that she had to go home straight after her talk and look after her children. When Joey explained to her that the Deputy CE would actually open the meeting, Lexi puffed and her mood seemed to change suddenly for the worse.

As seen from this example and from others observed during fieldwork, relations could be strained if volunteers believed that professionals were not fulfilling the duty to involve and consult, and instead were informally bending that legal requirement in ways that eroded the rights of CHCs and LINKs. As Joey stated on my last day of fieldwork:

Well, I can tell you, really, because it's not gonna be published until hopefully it's resolved. At the moment our relationship with the health board is quite strained [...] We don't always see eye to eye and we do have strained periods of time whereupon we go through periods where communication is quite difficult between the two organisations. Hopefully we're trying to resolve that through negotiations and discussion with the senior executives but...only time will tell that!

CHCs and LINKs devised various strategies to maintain friendly relationships with professionals, such as deciding not to take the opportunity of making an unannounced visit. Deliberations on whether to make such visits revealed the context within which officers and volunteers attempted to establish good relations. In an interview, Dan of Rainbow CHC stated:

Inspection isn't just about catching people out – it's about engaging with people to improve quality [...]! But I know the lay view is...that all visits should be sort of unannounced, but you can't get the same information; you need briefing and understanding [...] Then you just set up conflict – for what purpose?

CHCs and LINKs did not want to erode good relationships that had been established through personal bonds and hard work in gaining trust. Tanya in Red LINK asserted that volunteers had to “keep the relationships [with the NHS] as amicable as you can”. Renegotiations of roles aimed to prevent professionals from perceiving them as “nosy”, “pushy” or “threatening” (these adjectives were used frequently by volunteers). A telling example concerning both LINKs occurred when they were in the process of negotiating a protocol to regulate ‘enter and view’ visits in local health services. When three NHS managers attended a key meeting to approve the final draft of such protocol, they arrived late, which was not appreciated by the LINK volunteers. This incident reflected Schwartz’s (1974) argument regarding the relationship between individuals’ power and waiting: the lower the social positions of individuals, the greater (and more changeable) the waiting time that is assumed tolerable. Gary displayed frustration with and incomprehension of why the PCT required such a prescriptive layer of rules when the legislation already offered some guidance about this activity, and expressed his disagreement several times when this issue was raised. In interview Gary admitted that “we need their cooperation, ‘cause

we don't have the power...we had kind of to agree to it but I didn't particularly want to". His sentiment was one of resignation; it was apparent that participants could not influence the decision on whether or not they needed such a document. The symbolic meaning of this document was a powerful one: it represented professionals' interpretation of their working relationship with the LINKs, and it forced a change in the volunteers' code of conduct and reformulated the meaning of visits to be consistent with the NHS view of visits. "In the spirit of collaboration", as one senior manager from the PCT put it, volunteers were expected to comply with the new protocol. Similarly, a few other LINK volunteers noted that they had to phrase carefully their visit reports on their observations within hospitals. Sheila explained:

I have to be very careful what I'm putting in our report this month, and of course whatever I do will...or can work against the relationship that we have with the Trust, so it's all, you know – it's a huge responsibility for someone who is doing it on a voluntary basis and is an amateur. I know we all have our various strengths across participation but, you know, we're not all used to these sort of things and it's a, as I say, a huge responsibility.

Crucially, LINK volunteers' strategies for avoiding adverse relationships may have limited the inclusiveness of participation: persons who were deemed unable to comply with volunteers' established rules may have been excluded from certain activities, and thus been denied the opportunity to express their voice. For instance, Sheila stated:

I try to be careful about sending anybody I don't think would show LINK in a good way on visits – whether that's right or wrong I don't know, but then it would fall back on me if it all goes pear-shaped.

She strongly emphasised that her biggest responsibility was to demonstrate to NHS professionals that they could trust her, and that her actions aimed to fulfil that purpose. In a similar vein, Andy emphasised the need to involve only certain people in 'enter and view' visits:

That [visiting] requires people with knowledge and discernment...and dare I say people with intelligence. You can't have every Tom, Dick and Harry just walking around hospitals, you know, asking questions and they've got no idea.

Interestingly, the old Rainbow CHC developed a space for engaging in informal discussion with LHB professionals. They established 'liaison meetings' wherein the CO, Deputy CO, chair and vice chair of the CHC met with executive directors, nursing, planning, Chief Executive, community and mental health: in other words, as Joey explained, "senior executives to senior executives". After a brief experience as CO in the new Rainbow and Rural Hill CHC, Stephen also adopted the same arrangement in Blue Sand Hill CHC. I was denied access to these meetings because Joey noted that "they were more strategic than others", and therefore can only offer a tentative analysis based upon informants' accounts. Joey drew particular attention to the form of those meetings rather than providing information on the content of the discussions:

They're not minuted; there are just headlines taken of those meetings so we can have a very frank exchange of views in the meeting. They can tell us things in confidence; we can tell them things in confidence [...] We don't always see eye to eye and we say what we think and they say what they think, which is great 'cause it's not minuted. There's no sort of formal process for the minutes in that it's literally two groups talking of the hot issues which affect the health services locally.

Although the exact nature of the topics discussed was prohibited from 'going public', my reconstruction suggested that the information provided at liaison meetings complemented what professionals and members discussed at CHC meetings. The private setting of these meetings might have allowed CHCs to deviate somewhat from the expectations of total independence from the NHS by accommodating professionals' needs in ways that could have damaged their credibility in public arenas. Liaison meetings appeared to sustain the distance between the public and the services and also implied a patronising view of ordinary people and of the majority of CHC members, who were excluded in light of the delicate nature of the issues discussed. It may be inaccurate to assume that these meetings were real performances and that the observed meetings were staged: arguably, we can imagine a front-back

continuum (MacCannell, 1973) wherein front and back regions had fluid boundaries (Tardy, 2000), which were redefined through interactions in their social context.

Similarly, I observed an instance where Red LINK's management group was excluded from taking part in negotiations with the local CQC compliance manager. The rationale for this exclusion resembled that given in CHCs – certain discussions were open only to a very limited number of volunteers – and suggested that professionals imposed their terms upon the negotiation process. I report a short extract from my notes:

When the CQC manager arrived at the meeting, she observed all the people in attendance and asked, "I wonder if this is what I've asked for?" Joyce then said, "Oh, well, when you said the chairs, I thought you meant the chairs of the working group", and the CQC manager clarified: "Well, no, I just wanted to have a meeting with the two Chairs of the LINKs, but we are here so we are happy to stay to answer some questions and discuss things you'd like to". However she went on to say that they couldn't actually share their plans for the future with a large number of people since "there is a limit" to the amount of information they could provide. None of the volunteers contested her explanation or attempted to provide an alternative rationale as to why the whole management group should take part in such a discussion.

In the vast majority of cases volunteers and officers did not resist the terms of involvement defined by professionals, but rather sustained them through passive compliance.

PPI in the LA

As illustrated in Chapter One, LINKs' remit included social care as well. By contrast, CHCs only covered NHS-funded services although "Making the Connections: Delivering Better Services for Wales" (WAG, 2004) promoted a joined-up approach across public services and encouraged local partnerships. This discrepant approach affected the ways in which LINKs and CHCs interacted with LAs.

LINK officers broadly agreed on the difficulties encountered in establishing contacts with LA service managers due to the newly introduced role of the organisations to have a say about social care services. Greenshire LINK developed a good relationship with James, the monitoring officer, as he was already familiar with some of the volunteers involved. As noted in Chapter Five, Greenshire LA received a “five stars assessment”, which led some participants to argue that local people were quite happy with the services provided and that as such they had no reason to become involved. By contrast, Red LINK had to identify and create connections with relevant professionals; however, these connections appeared to be ‘swept away’ and volunteers “had to start all over again” whenever a new officer was employed. Joyce recounted how relationships progressed with Red LA over time:

[The Director of Social Services] had an understanding about LINKs, but she was a little bit concerned that, you know, we'd just be nosy people [she laughs], pushy people and we really had to kind of go softly, softly, 'cause she had this vision of what she thought it was going to be like.

This extract suggests that LA officers’ perceptions of volunteers and their involvement in social care services were similar to perceptions of NHS professionals. While officers and volunteers involved in social care renegotiated the conception of the LINK as a local stakeholder, LA officers attempted to renegotiate volunteers’ practices to conform to expected standards. For example, a Red LINK monitoring officer suggested that volunteers redefined their training system by “identify[ing] training needs beforehand”, with “knowledgeable members spend[ing] some time to identify the needs”, but did not offer to assist several volunteers with creating a comprehensive training programme embracing identified bottom-up needs. Further, James stated that it was a priority “to get the right sort of professional but independent perspective across, so that it can have a role as an equal partner”.

Although CHC’s remit did not cover social services, a number of local councillors were appointed as CHC members. Before the reconfiguration, particularly in Rainbow CHC, members expressed mixed feelings about councillors, generally reporting that attending CHC meetings was a secondary activity for local councillors due to their considerable workloads. When Simon was the CO, CHC representatives

regularly attended advisory planning groups as part of the LA Health and Social Care Wellbeing strategy: these groups focused on issues such as mental health, carers, homelessness and disability. The CHC thereby managed to understand local issues and Simon seemed very proud when describing the “level of infiltration” of the CHC. Informal relationships and informal flows of information constituted key aspects of CHC working practices. For instance, Rainbow and Rural County CHC officers used a flexible approach in dealing with the LA after the reconfiguration. Daniel, a veteran CHC member, recounted that he acted as the representative on the Local Service Board, a network of local public and voluntary sector organisations that “come together to take collective action to ensure public services are effective and citizen focussed” (WG, 2012) which was established as one of the partners responsible of fostering a joined-up approach locally. I am not aware of any Blue Sand Hill CHC members attending any equivalent local meetings. Rainbow and Rural County officers seemed to act intentionally in the spirit of local collaboration although, as one of them explained to me, “the LAs are under no obligation to acknowledge what we’ve said or even to act on it”.

By contrast, the old Blue CHC CO, Lianne, commented that “relationships [with the council] were very good ‘cause representatives [councillors] were very good”, but, like other volunteers, did not expand on this point. Blue CHC also had connections with the Health and Social Care Wellbeing strategy Group – as Lianne stated, “once you’re out of hospital it’s on to the council books you know so we had to be involved with them as well”. Local councillors appointed by the LA after the reconfiguration were far more involved than in Rainbow and Rural County CHC; a few of them even became chairs or vice-chairs.

After the reconfiguration, Ed repeatedly advocated for political neutrality in the CHC, which could not be seen to be allied to any political party. He also made a strong case, constructed mainly in legal terms, for drawing clear boundaries between the CHC’s remit and the area of social care. The following extract from my field notes relates an incident illustrating Ed’s views on this point:

A member raised the issue of care homes and how far they were a CHC responsibility as joint working with Social Services developed: “Will we be able to

go into care homes?” They had some discussion about this because at least one member thought that the line between the NHS and social care was quite unclear and that people were getting cared for in care homes. Ed intervened quite forcefully to say that the fact that somebody was being cared for in LA funded provision indicated that they did not require nursing and medical care. He said this area had thrown up a lot of problems in the last couple of years – especially with the private sector in West Wales – and warned members, ‘I have to make you aware of this because action could be taken against you as an individual’. There was some more discussion with members saying that the line was hard to draw. If it was privately-funded care, they couldn’t look at it.

This case of the past CHC visit in Wales was well-known to members and served as a powerful deterrent: Ed explained that “the owner [had] threatened to sue the individuals in the CHC because it could have ended up in a loss of business and possibly closure”. This cautionary tale, complemented by Ed’s strong view on the necessity of the CHC being seen as politically neutral, constituted the background for the concerns expressed by most volunteers about the possibility of working with the LA.

Juridification

The new duties and associated framework for CHCs were imposed from the top down, and similarly the White Paper “Equity and Excellence: Liberating the NHS” (DH, 2010) portrayed the government’s vision for the future of the NHS and LINKs. However, these statutory frameworks were still subject to interpretation by front-line actors in the process of planning and implementing PPI. I therefore draw on the concept of juridification (as discussed in Chapter Two) in order to supplement my interactionist analysis of the construction of meanings of PPI: to do so, I will discuss how micro-level interactions were shaped by front-line actors’ interpretations of top-down constraints.

As illustrated previously, despite regulations and the constraining influence of new duties and rules, practical decisions about how to enact PPI were often made in a

context of uncertainty. PPI was widely endorsed by policy documents and official guidelines, but at the local level was mainly viewed in legal terms and as “something that we have to do”. The lofty ideals of national PPI policies – the English pronouncement “everyone’s view matters” and the Welsh working definition of “constant and continuous engagement” – did not align with volunteers’ understandings, which tended to view PPI as “a slot” or “a bit” that was included in the legislation. Particularly in CHCs, officers contributed significantly to shape this view and the decision-making processes regarding PPI. Participants interpreted PPI as a peripheral activity distanced from the work of the organisations. By using simple proxies for involvement - such as the number of people attending meetings, the documents produced showing that the organisations established contacts with local people or that Red LINK sought to comply with the LA guidelines - constructed the evidence that PPI was proceeding.

In Wales, we have seen how the reconfiguration eroded the old organisational identity of CHCs and how the “Guidance for Engagement and Consultation on Changes to Health services” (WG, 2011) and also the CHC Regulations 2010 made PPI central to their daily work. However, officers were critical of the absence of a “blueprint” on how ‘to do’ PPI and expressed worries that they were not complying with their legal duties as set out in legislation. This aspect was particularly emphasised in Blue Sand Hill CHC, where officers reported that the lack of formalised past experiences in ‘doing PPI’ (through the identification of the duty with a dedicated officer) might affect their ability to achieve the requirements set out in the guidance and communicated to them through the Minister’s recommendations. In both CHCs though, informants were particularly concerned about showing evidence that they were doing PPI: as a result, officers were very attentive to document their activities by creating folders and lists of groups contacted.

LINKs also created a transition group to provide a space for participants to discuss their expanded duties and the new arrangements for regulating involvement as outlined in the White Paper “Equity and Excellence: Liberating the NHS” (DH, 2010). Volunteers expressed concerns about the Government’s future plans, the impending abolition of LINKs and the possible development of policies, particularly with regard to the effects of top-down changes on the motivations of people involved

at the grassroots level. In debating how the new profile of local Healthwatch might be developed, LINKs constructed narrow definitions of involvement that complied with their interpretations of the statutory frameworks as set out in written guidance. In both countries, actors arguably juridified the concept of PPI by emphasising its legal dimensions and the need to comply with their understandings of legislation as communicated to them in guidance or through national forums, such as the All Wales PPE Forums. Narrow operative definitions of PPI that mainly focused on activities imposed from above (such as engaging with certain percentages of local groups, establishing local connections that can be documented and organising consultation meetings that provide information about local changes in services) prevented informants from developing more inclusive and flexible understandings of the concept. Juridification occurred as actors adopted narrow interpretations of PPI centring on their understanding of the statutory frameworks that regulated LINKs and CHCs. As a practical implication, informants tended to align their conceptions of PPI with established activities that had characterised the previous working practices of PPI organisations.

Conclusion

This chapter explored how various stakeholders in citizen-engagement organisations constructed operative definitions of PPI. As Callaghan and Wistow (2006) contended, the negotiated process of policy implementation occurs through actors' interpretations of top-down policy, taking account of local contingencies. In this chapter, we have seen how both LINKs and CHCs acted under conditions of uncertainty wherein informants had to construct the meanings of PPI in everyday work. The comparative framework is thus valuable in identifying similarities and differences between England and Wales by examining the social processes through which actors reached their working definitions of PPI.

The chapter has discussed the interrelatedness of role constructions, social interactions, practical decisions and local contingencies in shaping the meanings of PPI in CHCs and LINKs. Actors in both systems, operating within different institutional constraints, needed to improvise roles and relationships and decided

what PPI meant. The Welsh and English legislations defined the insider group in their respective citizen engagement organisations differently, suggested differing expectations of commitment (the ideal of inclusiveness for LINKs and that of a top-down appointment of CHC members) and rather different tasks. The volunteer perceived their roles differently and this affected their relationships with paid employees and how they interacted in everyday activities. Constructions of PPI in the two countries therefore differed significantly in relation to top-down legal requirements and how front-line actors understood roles and relationships. In particular, members of staff shaped different expectations of the formal role of the volunteer in supporting the PPI work of the dedicated officers. However, more significantly, local stakeholders in both organisations similarly juridified PPI by emphasising the need to comply with the legal dimensions of the concept at the expenses of other aspects of the policy – such as the type of information provided, access-related issues and the respect of social differences and needs.

Participants' juridified interpretations of PPI may have been detrimental to the integration of PPI into the core work of CHCs and LINKs, and probably led to the exclusion of volunteers from relevant decision-making arenas. In addition, this process may have restricted opportunities for proper deliberation regarding bottom-up concerns and demands of involvement. NHS professionals, officers and volunteers contributed to the exclusion of local people and the wider organisational membership of the organisations from key discussions about local services and future plans – such as liaison meetings, and discussions with professionals.

PPI was a secondary activity in relation to CHCs' core work, and this was reflected in the observation that the vast majority of volunteers and officers saw their traditional activities as the cornerstone of that work. With a few notable exceptions, the majority of LINKs' volunteers shared a similar perspective although members of staff were certainly keen to do involvement, but in ways that reflected their legal understandings of PPI. Overall, this resulted in a marginalisation of PPI work; it affected the selection of issues for discussion, discouraged some potential participants from getting involved and limiting opportunities for more imaginative local initiatives to expand the range of involvement activities.

CHAPTER TEN

CONCLUSION

Introduction

This thesis explored comparatively the construction of the meanings of PPI policies by recruiting two Welsh CHCs and two English LINKs as sites for examining everyday practices in local arenas. Drawing on observational data, interviews and documents, the study aimed to provide a better understanding of the processes at work via the involved stakeholders (i.e. volunteers, officers and professionals) who had to interpret and enact PPI policies. The research was also particularly concerned to situate front-line actors' views and decision-making in the context of Welsh and English NHS policies and statutory frameworks: it thus examined how they interpreted top-down policies and made sense of PPI in the course of the work.

This concluding chapter discusses the empirical findings by reviewing the processes through which informants constructed the meanings of PPI policies. The premises of symbolic interactionism (see Chapter Two and Three) remind us that we can only provide tentative and emergent analysis of actors' social worlds: these conclusions must therefore be considered provisional (Rock, 2001). In addition, the chapter examines the sociological contributions of the study and the policy implications that it raises; it provides a critical evaluation of the thesis and lastly it suggests some opportunities for future lines of enquiry.

The policy and statutory frameworks for LINKs and CHCs: how front-line actors responded to top-down messages

In England, LINKs were characterised by the principle of inclusiveness. This was a central theme in the guidance published by the DH and NHS Centre for Involvement, which supported an 'everyone is welcome' approach that aimed to expand local participation in order to enable any local person to express a view on health and

social care services, whether via regular attendance at meetings or one-off activities (see Chapter Five). Accordingly, there was no specific threshold in guidance regarding the degree of commitment expected. But different, and sometimes conflicting, understandings of roles resulted in tense relationships between volunteers and employed staff, which at times affected the depth of discussion in meetings. In addition, despite the creation of a deliberately permissive regime, experienced LINKs volunteers found it hard to make the transition from older PPI organisations that were prescriptive about work roles to the more flexible “network” arrangement in which local actors could improvise their own roles (see Chapter Five). As a result, volunteers established informal practices about what the role of the LINK volunteer entailed as a strategy to reproduce and maintain an organisational order similar to the one experienced in the pre-existing public involvement forums. These informal practices often introduced tensions into the new network framework.

By contrast, the Welsh legislation regulated the composition of CHCs by a top-down appointment of members, which required candidates to comply with a detailed list of characteristics and skills in order to undertake the member’s role (see Chapter Six). Officers were viewed as a valuable asset for CHCs in light of their skills and knowledge, and volunteers trusted their competence in advancing the work of the organisations. During the early phase of research this resulted in more harmonious working relationships than those observed in LINKs. The 2010 reconfiguration represented a turning point for Blue Sand Hill CHC, and - after that change - many respondents claimed that “WAG got the wrong people” by selecting individuals that did not comply with the role expectations of insiders. My data showed that officers and experienced volunteers resisted new role definitions introduced by incoming members by highlighting the need to comply with the primary tasks of the organisations, such as monitoring visits (which were viewed as core CHC work). However, members were also having to adjust to recent legislation, emphasizing the duty to engage in PPI activities (CHCs Regulations, 2010; WG 2011), and which the officers and senior managers realised the CHC needed to show it was acting upon by demonstrating compliance with top-down requirements. Thus the traditional understandings of more experienced volunteers were being challenged both by the changing membership and new top-down pressures to readjust the focus of the work.

The differing constitution of LINKs and CHCs in England and Wales created a natural experiment that helps us to assess how far differences in institutional arrangements translate into operative differences in definitions of PPI and the nature of engagement work. They illustrate the differing conjunctions of benefits and dis-benefits that emerge when the boundaries between core participants and the general public are drawn more or less inclusively, and the positions of those entrusted with the bulk of the work are protected either by closed formal membership (in the case of CHCs) or the construction of informal in-group norms and practices (as happened with LINKs). LINKs achieved greater inclusiveness, but then had to deal with the tensions and disharmony this engendered and deviated somewhat from the intended policy blueprint when experienced volunteers re-interpreted and adapted their role so as to reproduce some of the work practices found in the old involvement forums. Only the appointed members could participate regularly in CHCs, and this translated into less impressive achievements in terms of the scope of engagement and range of participants, resulting in an instruction from the then Health Minister to make greater efforts to involve hard-to-reach groups. However, prior to the 2010 restructuring, CHCs experienced less internal friction and a greater sense of continuity with previous activities than did LINKs. The impression of difference was significantly reduced after the 2010 reorganisation when new tensions appeared within CHCs.

Indeed, overall it was the similarities in perspectives on PPI, as well as the similar practical activities that engagement work involved, that the study found to be more striking than the differences. This may reflect the common origin of both systems in CHCs (which existed in England until their abolition in 2003), and the fact that many experienced volunteers and officers in both England and Wales had worked through a series of reforms over many years. In both countries, local stakeholders had considerable space for negotiations regarding everyday work, albeit within certain institutional constraints. Despite different legislation regulating the work of LINKs and CHCs, informants in both countries constructed similar understandings of the staff and volunteer roles as closely aligned to the core functions of the respective engagement bodies. Thus the provisional finding of my study is that recent changes in institutional arrangements had had only limited impact by the time of fieldwork. That may change as the common history of LINKs and Welsh CHCs in the old pre-

2003 CHCs recedes further into the past, but one may hypothesize that in the short-term the culture and established ways of seeing of experienced participants has as much influence on what they do as the changing institutional arrangements.

Everyday practices of PPI in local arenas

English and Welsh volunteers explained their place in their organisations with reference to positive personal attributes, such as acting in the interest of ‘the public’ or showing awareness of wider issues. But a way of thinking that portrayed volunteers’ involvement as a consequence of their positive attributes also led to negative constructions of members of the general public, who were perceived to lack the appropriate qualities and skills for full participation, and thus created a symbolic divide between volunteers and the ordinary people whom they served. In addition, with a few exceptions in LINKs, respondents perceived the public as unable to conform to insider perspectives concerning organisational working practices.

Volunteers and officers in both organisations conceptualised their roles and responsibilities in terms of the performance of certain discrete tasks. Participants in both CHCs and LINKs bemoaned a lack of detailed instructions on how ‘to do PPI’. Indeed while the government’s idea of local determination represented an opportunity for involved stakeholders to develop meanings and practices that embraced bottom-up needs and demands, most respondents appeared to prefer a more prescriptive framework, with instructions about what to do, and how the work should be done. Paradoxically, the lack of detailed guidance on what PPI might entail, led participants to focus more narrowly on what the law stated it must entail as a minimum. Thus in practice, officers, volunteers and NHS professionals were mainly concerned with complying with the legislation and producing evidence that PPI was proceeding as required, or expected.

“We have to do it”: the juridification of PPI

Informants reported increasing concerns (particularly after the 2010 reconfiguration in Wales) to comply with top-down requirements related to the work of the organisations, but also to the pressure of “doing involvement” and establishing contact with local people. Participants juridified PPI by constructing its meanings mainly in legal terms. This meant that they often used crude proxies to demonstrate that the involvement required by the legislation was taking place (see Chapter Nine).

Although policy documents hinted at multiple differing conceptions of PPI, involved stakeholders (including NHS professionals) narrowed the range of working definitions of PPI as they juridified the policy to focus on the core statutory requirements. My empirical data suggested that employed officers had a significant role in shaping understandings of PPI as complying with the legal duties set out in legislation. Simultaneously they generally sought to align such duties as far as possible with the traditional activities of the organisations. This translated into a reluctance to accept alternative emergent definitions of PPI, or ways to pursue involvement. At times, in fact, such legal understandings left participants ‘doing’ PPI because they were told to do so. They found it hard to construct the policy in positive terms, because of their overwhelming preoccupation with the need to comply with the duty to involve, which appeared to promote an understanding of involvement mainly as a policy against which they may be negatively evaluated. The analysis also highlighted that legal interpretation of the concept may limit reflexivity concerning how participants define their responsibility for building PPI.

Sociological contribution

When I opted to embark on a symbolic interactionist study, my primary intention was to show the relevance of that approach to an applied policy area rather than to generate new symbolic interactionist theory. However, the thesis offers a modest theoretical contribution by exploring public-facing bodies with relatively open boundaries in which volunteers working along a small core staff are central to the work. Both CHCs and LINKs depended on a combination of paid staff, regular

volunteers and a wider range of involved people who feature from time to time in engagement activities. CHCs erected a formal boundary between these last two groups via membership by appointment, while in LINKs there were informal processes through which the regular participants distinguished themselves from the broader public. My study thus highlights both similarities and differences from the findings of Nelsen and Barley (1997) regarding paid and unpaid emergency medical technicians. In their study it was paid versus unpaid status that resulted in different identities and rhetorics justifying respective positions. The paid EMTs constructed an 'ideology of practice' emphasising their greater professional competence compared with the amateurs, while the volunteers pointed out that the paid EMTs did the job for the money and lacked altruism. This contrasts with the situation of CHCs and LINKs, where, although the tiny core staff and involved healthcare professionals did differentiate themselves from volunteers, the more visible contrast was between the regular volunteers and members of the public who became involved on an occasional basis. Thus in the engagement bodies it was the ideology of the good volunteer (or in my terms the complex of meanings around volunteering), rather than any ideology of good staff practice, that came to the fore. This reflects the fact that PPI bodies were tasked with overseeing public involvement activities and necessarily had to demonstrate their engagement with that public. They were not on the same trajectory of transition whereby participants were moving over time from informal to formal work roles that characterised the situation of US Emergency Medical Services.

Despite recognising that there exist several forms of involvement, O'Keefe and Hogg (1999) asserted that "we have come a long way from the position that the professional knows best" (p.246). As mentioned in Chapter 2, several studies suggest that professionals may dilute or otherwise channel citizen involvement to minimise its impact on decision making (Hodge, 2005; Martin, 2008a; Renedo and Marston, 2011). My study did not find the more obvious forms of control or steering of volunteers reported in the earlier studies; instead it was the efforts of experienced volunteers to impose their definitions on fringe participants that were most visible. However, professionals remained a powerful group, often exercising subtle influence and viewing themselves as responsible for "a lot of thinking in planning changes to the services". Professionals' expectations of volunteers emerged from their ideas of

what represented a valuable contribution to NHS services and they did not recognise the value of some working practices that volunteers considered relevant in discussing health issues, such as the use of newspaper cuttings to inform their decision-making. Professionals largely regulated volunteers' involvement in the NHS – such as in 'enter and view' visits - and at times they limited access to some relevant information only to a few selected volunteers, such as Chairs and vice-Chairs (see Chapter Nine). Earlier studies also found that professionals shaped the forms and practicalities of volunteers' involvement (O'Keefe & Hogg, 1999; Rutter, Manley, Weaver, Crawford, & Fulop, 2004). The thesis thus confirms that issues of professional dominance described in the literature have a continuing relevance in the PPI domain. There still appears to be friction between the policy aspirations that CHCs and LINKs should reach out to and involve diverse public within their local communities, and the social and relational complexities of the systems in which volunteers operated.

My study provides further data bearing on the issue of the representativeness of involved volunteers. Particularly in CHCs, boundaries between 'representing the interests of people' and 'representing people' were quite blurred, and at times the meanings of the two tasks seemed to overlap in the course of the work. For many participants, the key aspect of the volunteer's role was not to represent public opinion, but rather to consider the 'bigger picture' and act upon an objective evaluation of the circumstances that 'the public' was unable to understand. Several informants acknowledged that CHCs and LINKs were not fully representative of the population in terms of socio-demographic status, but the findings suggested that appropriate personal attributes and the ability to look at 'wider issues' were deemed to be *the* fundamental characteristics for proper participation. There is a need for working definitions of representativeness and 'being representative' to emerge from bottom-up negotiations that reflect understandings of the volunteer's role as local participants make sense of them.

My data reveal a widespread perception that the ideal volunteer was a sensible all-rounder rather than a person with a non-conventional life history, such as a participant self-identifying with a particular group or community. In other words, it was compliance with informal understandings of the good volunteer constructed

within the organisations that really counted. The informal consensus among volunteers that “single issue” participants were less valuable than those who could contribute usefully on a range of issues may have led them to focus less on individual needs and problems. Inclusiveness has been an elusive goal for CHCs and LINKs, and was often neglected by insiders keen to ensure that the appropriate people complied with appropriate practices in sustaining good relationships with professionals.

It can be argued that there is a recurrent tension in many citizen engagement forums between positive volunteering to promote the public good and participation aimed only at defending particular sectional interests, and the latter may often be viewed in negative terms. This prevents the “capture” of organisations like CHCs and LINKs by single-issue groups, but the consequence may sometimes be that the voices of such groups are taken less seriously than they deserve to be. In examining parents’ involvement in children’s mental health services, Potter (2010) highlighted that local practices might challenge the rhetoric of participation by informally restricting access to institutional spaces only to people displaying certain personal attributes and compliance with shared understandings of the role, leaving some people’s views unheard. Involvement needs to be rooted in everyday acceptance of diversity beyond the rhetoric of inclusiveness.

The logic of PPI as expressed in both official policy statements and much of the academic discourse is that almost everybody is assumed to have the potential to contribute - regular volunteers, members of the public and anyone who wants to get involved in local organisations’ activities. It is thus crucial to promote the legitimacy of everyday forms of knowledge and the powerful role that members of the public can have in involvement practices in healthcare. Due to the well-established relevance of the social contexts of experiences of health and illness, and of interactions with professionals, it is vital to acknowledge that everyone has something valuable to offer in a variety of forms of involvement. This view is strongly supported by the interactionist perspective that recognises and values each individual’s contribution in constructing everyday social interactions. For instance, Wellman (1988) argued that “all of the cognitive activities necessary to get through a day are ‘knowledge’”. This kind of knowledge might not be expressed technically

with abstractions like formulas, equations, or theorems. But in Blumer's view it is nonetheless a type of knowledge and no less important than its technical counterparts" (p.63).

As noted in Chapter Six and Eight, engagement became a prominent aspect of the work of the CHCs as defined through the legal framework, but also via the policy framework as elaborated (and communicated) by the Minister of Health and Social Care. Similarly, the DH assigned a significant role to the LINKs as bodies responsible for bringing local individuals and community groups together and enabling them to express their views about health and social care services (see Chapter Five and Eight). The strong institutional focus on 'doing PPI' as perceived by informants translated into an increasing concern to demonstrate compliance with top-down messages and to provide tangible evidence of involvement. Indeed the production of evidence became a prominent feature of the work of CHCs and LINKs. The notion of juridification illuminates the interrelatedness of constructions of meanings, informal roles expectations and working practices in the joint action (Blumer, 1969) via which participants make sense of PPI. In terms of the debate within negotiated order theory mentioned in Chapter Two, institutional context - particularly the legal framework - put limits on the possibilities for negotiation at least in respect of what the core duties of CHCs and LINKs were. Negotiations were commonplace when it came to organising day-to-day activities, but on the matter of minimum obligations the law was paramount. As in Allen's (2008) study (regarding doctors' and nurses' work roles), the issue here was not so much re-negotiating rules fixed by higher-level actors, but rather an ongoing process of sense-making via which participants accomplished their meanings.

Policy implications

The findings offer a number of practical lessons for policy-makers and NHS and local authority based practitioners. Ultimately, it is hoped that the empirical knowledge generated through the study may contribute to policy, practice and future research.

The primary intention of the thesis was to apply the established approach of symbolic interactionism to LINKs and CHCs and the domain of participation in health-care, which can be considered areas of applied research where this theoretical perspective is not usually utilised. The study showed that symbolic interactionism can offer valuable insights about the construction of a concept, and the enactment of policy. It offers an approach for exploring in detail the processes of implementing and operationalising a policy blueprint communicated by the central government departments to local agencies and actors, and the way lower level actor interpret and act out these policies in practice.

Volunteers and officers interpreted the absence of nationally-led initiatives to raise the profile of the organisations as symbolically reinforcing the subordinate position of CHCs and LINKs to professional dominance. One suggestion emerging from the research therefore is that Governments in the two countries should change the tone of policy documents to include a clearer endorsement of LINKs/CHCs and the value of the volunteer role. This would strengthen the position of volunteers in their dealings with professionals and hopefully reduce power imbalances in relationships. It would be beneficial to create learning opportunities for professionals at various levels of the managerial system about the existence of statutory mechanisms of involvement, and their own obligations in terms of taking public engagement seriously. Indeed each volunteer's and would-be participant's contribution must receive serious consideration if PPI policies aim to create a balanced combination of professional and lay views.

Further, my study showed a degree of uncertainty and concern with the clarity of PPI policies that suggests that government is not doing enough to support these bodies. Government needs to provide adequate resources to support current policies and enable the organisations to meet volunteers' different needs. The limited availability of financial support forced CHCs and LINKs to make difficult choices about the practicalities of everyday work, particularly in relation to accessibility. For instance, informants in both LINKs and CHCs identified the lack of translation services as an obstacle to involving ethnic communities whose members find it hard to communicate in English. National and local policy-makers should be made aware of everyday practicalities of this kind. However, due to current severe financial

constraints, and difficult decisions about investment and disinvestment, it is acknowledged that this may be a controversial topic of discussion at governmental level.

The study showed that recent top-down changes in PPI arrangements had damaged volunteer morale, leading participants to express frustration at the idea of adjusting to new practices and 'starting all over again'. In the White Paper "Equity and Excellence: Liberating the NHS" (DH, 2010) the coalition government set out plans to make substantial alterations to the English NHS and to English PPI arrangements. This followed hard on the heels of the changes to the organisational structure of CHCs as part of the WAG's 2010 restructuring of the NHS in Wales. The findings suggest that policy makers underestimated the negative consequences that rapid and major service changes would have on PPI arrangements in practice. Given the fragility of involvement and the length of time it takes citizen-engagement bodies to develop stable working practices and a sense of identity, there seems to be a strong case for limiting further major reform in this area until the latest arrangements settle. Participants interpreted the recent changes as disruptive in terms of undermining existing relationships. Particularly in England, where statutory organisations faced a series of successive reforms over a ten year period culminating in the recent transition to Local Healthwatch, employed staff and volunteers emphasised the importance of establishing their identity in the public realm and in professionals' arenas by developing long-term strategies in a period of stability. Interestingly, NHS professionals generally expressed a different view by stating support for the reforms and defining them as providing 'unique opportunities' to improve organisational working practices. These findings suggest that a period of stability for PPI bodies may be needed if the damage to volunteer morale is to be repaired. Indeed it would be a mistake to underestimate the enormous emotional and personal investment of volunteers in both countries. National policy-makers should show ongoing commitment to the existing organisational arrangements in order to enable local PPI bodies to establish themselves and carry out long-term projects with their communities. By doing that, these bodies will truly be in a position to show how they impact on the provision of health and social care services; furthermore, stability in

the system could ensure that CHCs and Local Healthwatch become integral parts of the lives of local communities.

Additionally, my study provided interesting insights into volunteers' perspectives on the idea of Big Society as it was launched by Prime Minister David Cameron in 2010. English participants were generally sceptical about the concept. Despite acknowledging its rhetorical power, most expressed cynicism and disillusionment regarding the practical implications of the Big Society. The larger role for community volunteers was seen by many informants as "cheap labour" providing services that were not otherwise financially sustainable. These negative perspectives may be explained by drawing on Brewer's (2011) and Sennett's (2012) contention that the idea of Big Society is intrinsically linked to the prospect of financial cuts in public spending¹. Some LINKs participants noticed the disjuncture between Government lip-service to a Big Society policy that emphasised the importance of community involvement and yet another change to PPI institutions that they saw as undermining their ability to contribute effectively to local health services.

As noted by several informants in both countries, the boundaries between health and social care provision were often confusing in practice. While LINKs in England cover both areas, Welsh CHCs are concerned primarily with the health domain. Due to the inextricable overlap of the two areas in practice, it may be worth considering the idea of creating statutory opportunities for user involvement in social care in Wales, so that the work of CHCs is expanded to cover the monitoring of social services. Clearly, this reorganisation would require purpose-designed training provision for officers and volunteers. In England, LINKs participants expressed positive views on the organisation's remit covering both health and social care services (and Local HealthWatch will still cover social care services). Drawing on such evidence, it seems reasonable to suggest that WG considers the idea of establishing equivalent formal arrangements for looking at social care in Wales.

¹ Lindsey and Bulloch (2013) also reported that the preliminary findings of their study exploring perspectives of the Big Society among volunteers showed that the majority of informants expressed negative views about it.

Critical evaluation of the thesis

As much as researchers endeavour to conduct substantial studies, limitations will inevitably arise and affect the study results. I therefore now address some methodological limitations that I encountered in my own research.

In view of the limited scope of a doctoral study and of practical choices based upon travel costs and location, I considered two Welsh CHCs out of the nineteen that existed before the reconfiguration and the seven new CHCs formed after March 2010. Similarly, I examined two LINKs out of a total of one hundred and fifty in England. Although my findings may not be strictly generalizable (the research settings were not randomly sampled), the pragmatic combination of contingencies that shaped the selection of the research sites allowed me to consider organisations located in a large urban area along with equivalent bodies covering mixed provincial and rural areas that reflected the mixed geographical profile of Wales and England. Yin (1999; 2009, Chapter One) contended that case-studies can be considered as experiments and related findings provide “analytic generalizations” (Yin, 2011, Chapter One, p.18) rather than statistically representative results. I believe that the depth of the ethnographic descriptions provided in the thesis sheds light on social processes that might develop not only in other CHCs and LINKs, but in similar organisations. I also believe that my study does constitute an empirical contribution to the broad topic of public participation policies – specifically, with regard to the social processes through which involved actors developed certain ideas and enactments of participation. In other words, although ethnographic investigations do not necessarily attempt to provide generalizations, researchers may nevertheless learn from the meanings and the interactions examined in this project and test them in further case studies investigating contexts and interactions similar to those described in this thesis (Stake, 1978).

Also, the research might have developed differently if the organisations presented a “super-diverse” (Vertovec, 2007, p.1024) membership, if it included more young people or a larger number of NHS professionals. Under-explored social characteristics such as age and ethnic composition certainly affected the writing of

the thesis, so that it was difficult to consider fully how far these factors may have shaped everyday interactions of roles and involvement, or images of “the public”.

Another limitation of the study may be related to the lack of formal approval for access to some NHS sites at the periphery of the study (where participating professionals were based). The decision not to interview professionals or observe meetings on NHS premises, meant that a few events with marginal significance were not attended and stopped me seeking interviews with professional staff who stayed away from the public PPI arenas.

In addition, as alluded to previously, I was probably over-cautious in the early days of my fieldwork; the need to sustain my involvement with the organisations led me to refrain from asking to audio record meetings, and I decided to rely purely on my written notes in order to avoid “violat[ing] the problem’s natural integrity” (Athens, 2010, p.95). This decision affected the nature of my data. However, I collected a substantial corpus of fieldnotes for a more traditional ethnographic analysis, and overall I believe that this was an appropriate decision given the social context. Further, I was permitted to listen to some discussions that participants explicitly classified as “off the record”, and I felt that using audio-recording equipment might have hindered the natural flow of these interactions.

Murphy and Dingwall (2003) contended that

The responsibility for deciding the extent to which it is reasonable to draw general conclusions from the findings of a particular study will, in the end, always be invested in the reader of research reports. Such decisions will always be a matter of judgement (p.112).

Drawing on Seale’s (1999) work, these authors go on to explain that the reader’s judgement is significantly shaped by the researcher’s ability to provide a convincing portrayal of the conduct and characteristics of the study. It is hoped that earlier chapters have provided sufficient information to allow the readers to make such judgements.

Suggestions for further research

Within Britain, there is a need for more research on PPI organisations. To the best of my knowledge little work has been done in Scotland and Northern Ireland, where the Scottish Health Council and the Patient and Client Council currently operate. It may be instructive to examine how involved stakeholders understand and ‘do PPI’ in these countries in relation to specific devolved policies, and whether different institutional contexts reflect different approaches at grassroots level. Studies of this kind would help provide a more comprehensive picture of the impact of devolved policies and the extent of national variation within the UK.

A further line of enquiry would develop the foundations laid in this study by following the progress of the new English bodies, Local Healthwatch, their relation with the government’s idea of the Big Society and the impact of the changed legislation. The expectation that Local Healthwatch will establish strong local partnerships is particularly intriguing, given the loose nature of the current local networks. It would be useful to investigate the operational differences between LINKs and LHW and examine how the new bodies make sense of government policy and how they interact with the newly formed Clinical Commissioning Groups.

As mentioned in Chapter Three, my observations and interviews were carried out mainly at the local level and I did not collect data on higher-level policy networks: a study that involves politicians and NHS executives may offer an insight on top-down understandings of PPI and how those affect the ways in which they are communicated to front-line actors.

Future research agendas may also concern the exploration of bottom-up involvement in relation to other social contexts such as education, environmental initiatives and Science Technology and Society in order to investigate whether, and how, different associational forms shape differently the meaning of participation and the associated interactions.

Despite the methodological challenges that it may pose in recruitment, it might be informative to explore the views of people who do not participate, or ended their involvement in PPI institutional arrangements. Non-participants’ viewpoints are not

included in this study as I recruited informants via the CHCs and LINKs who were already actively committed. There is a gap in knowledge about some sections of “the public” with regards to how they view participation and the obstacles associated with it, and we should be careful to avoid easy dismissal of non-conforming attitudes. Fudge et al. (2008) remind us that “it is perhaps also an assumption of the policy that everyone wants to be involved” (p.7).

Conclusion

My study has shown the value of symbolic interactionism in investigating “the dense texture of everyday life” (Stolte et al., 2001, p.387) through which informants “did PPI”. Interactionist ethnographies have great potential power for exploring and comparing how informants involved in different organisations or settings make sense of their roles and the contexts in which they interact. After a period when they have rather fallen out of fashion because of access difficulties and the quicker results yielded by other methods, one hopes that a new generation of researchers will recognise the promise of field studies. This study has demonstrated that symbolic interactionism is indeed appropriate to the exploration of social processes in organisations and highlights the importance of the small details and subtle symbols that shape actors’ participation in everyday interactions.

REFERENCES

- Abbott, A. (2009). Organisations and the Chicago School. In P.S. Adler (Ed) *Oxford Handbook of Sociology and Organisation Studies: Classical Foundations*. Oxford: Oxford University Press.
- Adams, J. (2004). The Imagination and Social Life. *Qualitative Sociology*, 27(3), 277-297.
- Allen, D. (1997). The nursing-medical boundary: a negotiated order? *Sociology of Health and Illness*, 19(4), 498-520.
- Allen, D. (2001). *The Changing Shape of Nursing Practice: The Role of Nurses in the Hospital Division of Labour*. London:Routledge.
- Allen, P., Townsend, J., Dempster, P., Wright, J., Hutchings, A., & Keen, J. (2012). Organisational Form as a Mechanism to Involve Staff, Public and Users in Public Services: A Study of the Governance of NHS Foundation Trusts. *Social Policy & Administration*, 46(3), 239-257.
- Anderson, B. (1983). *Imagined Communities: Reflections on the Origins and Spread of Nationalism*. London: Verso.
- Anderson, T.L., & Bondi, L. (1998). Exiting the Drug-Addict Role: Variations by Race and Gender. *Symbolic Interaction*, 21(2), 155-174.
- Anderson, E., Shepherd, M., & Salisbury, C. (2006). 'Taking off the suit': engaging the community in primary health care decision-making. *Health Expectations*, 9, 70-80.
- Anthony, A. (2012, June 12). Richard Sennett: 'Big Society? It's to keep the bankers happy...'. *The Observer*. Retrieved from

<http://www.theguardian.com/theobserver/2012/feb/12/richard-sennett-sociologist-big-society>

Arnstein, S.R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35, 216-224.

Athens, L. (2010). Naturalistic Inquiry in Theory and Practice. *Journal of Contemporary Ethnography*, 39(1), 87-125.

Atkinson, P., & Silverman, D. (1997). Kundera's Immortality: The Interview Society and the Invention of the Self. *Qualitative Inquiry*, 3(3), 304-325.

Baggot, R. (2005). A funny thing happened on the way to the Forum? Reforming Patient and Public Involvement in the NHS in England. *Public Administration*, 83(3), 533-551.

Barnes, M., Newman, J., Knops, A., & Sullivan, H. (2003). Constituting 'the public' in public participation. *Public Administration*, 81(2), 379-399.

Barrett, S. (2004). Implementation studies: time for a revival? Personal reflections on twenty years of implementation studies. *Public Administration*, 82, 249-262.

Bauer, M., Mcauliffe, L., & Nay, R. (2007). Sexuality, health care and the older person: an overview of the literature. *International Journal of Older People Nursing*, 2, 63-68.

Bauman, Z. (1994). Alone Again. Ethics After Certainty. Retrieved from <http://www.demos.co.uk/files/aloneagain.pdf>

Bechky, B.A. (2006). Gaffers, Gofers, and Grips: Role-Based Coordination in Temporary Organisations. *Organisation Science*, 17(1), 3-21.

Becker, H.S, & Carper, J. (1956). Elements of Identification with an Occupation. *American Sociological Review*, 21, 341-348.

Becker, H.S., Geer, B., Hughes, E.C., & Strauss, A. (1964). *Boys in White: Student Culture in Medical School*. Chicago: University of Chicago Press.

Becker, H.S. (1970). *Sociological Work*. Chicago: Aldine Publishing Company.

Becker, H.S. (1996). The Epistemology of Qualitative Research. In R. Jessor, A. Colby, & R. Shweder, (Eds) *Ethnography and Human Development: Context and meaning in Social Inquiry* (pp. 53-71). Chicago: University of Chicago Press.

Benson, J.K. (1977). Organisations: A Dialectical View. *Administrative Science Quarterly*, 22(1), 1-21.

Bittner, E. (1967). The policy on skid-row: a study on peace keeping. *American Sociological Review*, 32(5), 699-715.

Blichner, L & Molander, A. (2005). *What is juridification?* Working Paper 14, Arena Centre for European Studies. University of Oslo. Retrieved from https://www.sv.uio.no/arena/english/research/publications/arena-publications/workingpapers/working-papers2005/wp05_14.pdf

Blumer, H. (1962). Society as symbolic interaction. In A.M. Rose, (Ed) *Human Behaviour and Social Processes* (pp. 179-192). London: Routledge.

Blumer, H. (1969a). *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall.

Blumer, H. (1969b). Collective behavior. In Lee, A.M. (Ed). *Principles of Sociology (3rd Ed)*. New York: Barnes and Noble Books.

Blumer, H. (1971). Social Problems as Collective Behavior. *Social Problems*, 18(3), 298-306.

Blumer, H. (1973). A note on symbolic interactionism: reply to Huber. *American Sociological Review*, 38, 797-798.

Blumer, H. (2004). *George Herbert Mead and Human Conduct*, Edited by T.J. Morrione. Walnut Creek, CA: AltaMira Press.

Board of Community Health Councils in Wales (2009). *Hospital Patient Environment External Assessment Visit. Annual Report, 2009*. Retrieved from <http://www.wales.nhs.uk/sitesplus/documents/903/HPE%20Annual%20Report%2020091.pdf>

Board of Community Health Councils in Wales (2010). *Annual Report 2009-2010*. Retrieved from <http://www.wales.nhs.uk/sitesplus/documents/899/ANNUAL%20REPORT%202009-10.pdf>

Bochel, D., & MacLaran, M. (1979). Representing the Interests of the Public?: The Case of the Local Health Council in Scotland. *Journal of Social Policy*, 8(4), 449-472.

Borer, M.I. (2006). Important Places and Their Public Faces: Understanding Fenway Park as a Public Symbol. *The Journal of Popular Culture*, 39(2), 205-224.

Borer, M.I. (2010). From Collective Memory to Collective Imagination: Time, Place and Urban Redevelopment. *Symbolic Interaction*, 33(1), 96-114.

Bosk, C.L. (1979). *Forgive and remember: managing medical failure*. University of Chicago Press.

Brewer, J. (2010, May 20). *What's wrong with the Big Society?*
Retrieved from
<http://sociologyandthecuts.wordpress.com/2011/05/20/what%E2%80%99s-wrong-with-the-big-society-by-john-brewer/>

British Sociological Association (2002). *Statement of ethical practice for the British Sociological Association*. Durham: BSA.

Bruni, A. (2006), Access as Trajectory: entering the field in organisational ethnography, *Management*, 3(9), 137-152.

Burgess, R.G. (1984). *In the Field: An Introduction to Field Research*. Routledge.

Callaghan, G., & Wistow, G. (2006) Governance and public involvement in the British National Health Service: Understanding difficulties and developments. *Social Science and Medicine*, 63, p. 2289-2300.

Campbell, C. & McLean, C. (2002). Ethnic identities, social capital and health inequalities: factors shaping African-Caribbean participation in local community networks in the UK. *Social Science & Medicine*, 55(4), 643-657.

Carlyle, E. R. (2012). *Sheepdog or watchdog? The role of statutory public involvement institutions in political management of the NHS, 1974-2010*. PhD Thesis, Birkbeck, University of London.

Carter, S.M., & Little, M. (2007). Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Research Methods in Qualitative Research. *Qualitative Health Research*, 17(10), 1316-1328.

Chapman, R. (2012). *Clinical Commissioning Groups – meeting statutory requirements on the duty to involve and consult during the transitional period and in the future*. NHS North of Tyne.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-195.

Charmaz, K., & Mitchell, R.G. (1996). The Myths of Silent Authorship: Self, Substance, and Style in Ethnographic Writing. *Symbolic Interaction*, 19(4), 285-302.

Charmaz, K. (2004). Premises, Principles, and Practices in Qualitative Research: Revisiting the Foundation. *Qualitative Health Research*, 14(7), 976-993.

Churchill, W. (1943, March). *A Four Year Plan for England*. Speech broadcast from London over BBC. Retrieved from <http://www.ibiblio.org/pha/policy/1943/1943-03-21a.html>

Clarke, J. (2005). New labour's citizens: activated, empowered, responsabilized, abandoned? *Critical Social Policy*, 25(4), 447-463.

Clegg, S. & Dunkerley, D. (1980). *Organisation, class and control*. London: Routledge.

Cohen, P. (1997). Beyond the Community Romance. Retrieved from http://www.amielandmelburn.org.uk/collections/soundings/05_29.pdf

Contandriopoulos, D. (2004). A sociological perspective on public participation in health care. *Social Science and Medicine*, 58, 321-330.

Consumers Health Forums of Australia (2013). Retrieved from <https://www.chf.org.au/>

Cowden, S., & Singh, G. (2007). The 'User': Friend, foe or fetish? A critical exploration of user involvement in health and social care. *Critical Social Policy*, 27(1), 5-23.

Cowell, R., & Martin, S. (2003). The joy of joining-up: modes of integrating the local government modernisation agenda. *Environment and Planning C: Government and Policy*, 21, 159-179.

Cox, D. (1991). Health service management – a sociological view: Griffiths and the non-negotiated order of the hospital. In Gabe, J., Calnan, M., Bury, M. (Eds). *The Sociology of the Health Service*. London: Routledge.

Cox, S.M, Kazubowski-Houston, M., & Nisker, J. (2009). Genetics on stage: Public engagement in health policy development on preimplantation genetic diagnosis. *Social Science and Medicine*, 68, 1472-1480.

Daudelin, G., Lehoux, P., Abelson, J., & Denis, J.L. (2010). The integration of citizens into a science/policy network in genetics: governance arrangements and asymmetry in expertise. *Health Expectations*, 14, 261-271.

Day, R., & Day, J.V. (1977). A Review of the Current State of Negotiated Order Theory: an Appreciation and a Critique. *The Sociological Quarterly*, 18(1), 126-142.

Day, G. (2006). *Community and Everyday Life*. Routledge.

Daykin, N., Evans, D., Petsoulas, C., & Sayers, A. (2007). Evaluating the impact of patient and public involvement initiatives on UK health services: a systematic review. *Evidence and Policy: A Journal of Research, Debate and Practice*, 3(1), 47-65.

Denzin, N.K. (1970). Symbolic Interactionism and Ethnomethodology: A Proposed Synthesis. *American Sociological Review*, 34(6), 922-934.

Department of Health (2004). *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. London: Department of Health.

Department of Health (2006). *A stronger local voice. A framework for creating a stronger local voice in the development of health and social care services. A document for information and comment*. London: Department of Health.

Department of Health (2007). *Getting Ready for LINKs, planning your Local Involvement Network*. London: Department of Health.

Department of Health (2007). *Local Involvement Networks explained*. London: Department of Health.

Department of Health (2007). *Memorandum to the House of Commons Select Committee on Health: Inquiry into Patient and Public Involvement in the NHS*. London: Department of Health

Department of Health (2008). *Local Involvement Networks. Briefing for independent providers*. London: Department of Health.

Department of Health (2008). *Stronger voice, better care. Local Involvement networks (LINKs) explained*. London: Department of Health.

Department of Health (2008). *Involving people and communities. A brief guide to the NHS duties to involve and report on consultation*. London: Department of Health.

Department of Health (2008). *Real Involvement. Working with people to improve health services*. London: Department of Health.

Department of Health (2009). *The NHS Constitution. The NHS belongs to us all*. London: Department of Health.

Department of Health (2009). *The Handbook to the NHS Constitution*. London: Department of Health.

Department of Health (2009). *Helping the NHS put patients at the heart of care: The Patient and Public Engagement Support Programme 2009-10*. London: Department of Health.

Department of Health (2010). *Help shape your local health and social care. Your guide to Local Involvement Networks*. London: Department of Health.

Department of Health (2010). *Engaging and responding to communities. A brief guide to Local Involvement Networks*. London: Department of Health.

Department of Health (2010). *Equity and Excellence: Liberating the NHS* (Cm 7881). London: Department of Health.

Department of Health (2011). *Local Involvement Networks Annual Reports 2010-2011. Commissioning, Analysis and Intelligence Team*. London: Department of Health.

Department of Health (2013). *LINks Exchange*. Retrievable from <http://www.lx.nhs.uk/about/>

Dingwall, R. (1997). Accounts, interviews and observations. In G. Miller & R. Dingwall (Eds), *Context and method in qualitative research* (pp. 51-65). London: Sage.

Dingwall, R., & Strong, P.M. (1985). The Interactional Study of Organisations: A Critique and Reformulation. *Urban Life*, 14(2), 205-231.

Ellen, B. (2013). Cameron's quip to schoolchildren in Liberia marks him out as the class dunce. *The Guardian*. Retrieved from <http://www.theguardian.com/commentisfree/2013/feb/03/cameron-liberia-education-quip>

Emerson, R.M., Fretz, R.I., & Shaw, L.L. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland (Eds) *Handbook of Ethnography* (pp. 352-368). London: Sage Publications.

Fine, G.A. (1996). *Kitchens: The Culture of Restaurant Work*. Berkeley, CA: University of California Press.

Florin, D., & Dixon, J. (2004). Public Involvement in Health Care. *British Medical Journal*, 328, 159-161.

Forbat, L., Hubbard, G., & Kearney, N. (2009). Patient and public involvement: models and muddles. *Journal of Clinical Nursing*, 18, 2547-2554.

Forster, R., & Gabe, J. (2008) Voice or choice? Patient and Public Involvement in the National Health Service in England under New Labour. *International Journal of Health Service*, 38(2), 333-356.

Fraser, N. (1990). Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy. *Social Text*, 25(26), 56-80.

Fudge, N., Wolfe, C.D.A., & McKeivitt, C. (2008). Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal*, 336(7639), 313-317.

Giarelli, G. (2009). *Patient and Public Involvement in Healthcare Governance – Italy. Working paper*. Reflexive Governance in the Public Interest (REFGOV) Project, Services of General Interest, 6th European Framework Programme in Research and Development.

Gibson, A., Britten, N. & Lynch, J. (2012). Theoretical directions for an emancipatory concept of patient and public involvement. *Health*, 16(5), 531-547.

Goffman, E. (1959). *The presentation of self in everyday life*. Edinburgh: University of Edinburgh Social Sciences Research Centre.

Goffman, E. (2005). *Interaction ritual: essays in face-to-face behaviour*. New Brunswick, New Jersey: Aldine Transaction. (Original work published 1967).

Golden-Biddle, K., & Locke, K. (1993). Appealing Work: An Investigation of How Ethnographic Texts Convince. *Organization Science*, 4(4), 595-616.

Gora, J.A. & Nemerowicz, G. (1991). Volunteers: Initial and sustaining motivations in service to the community. *Research in the Sociology of Health Care*, 9, 233-246.

Graham, P.M. (2008a). Representativeness, legitimacy and power in public involvement in health-service management. *Social Science & Medicine*, 67, 1757-1765.

Graham, P.M. (2008). 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness*, 30(1), 35-54.

Graham, P.M. (2009). Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements. *Critical Public Health*, 19(1), 123-132.

Greener, I. (2003). Who choosing what? The evolution of "choice" in the NHS, and its implications for New Labour. *Social Policy Review*, 15, 49-68.

Greener, I. (2009). Towards a history of choice in UK health policy. *Sociology of Health and Illness*, 31(3), 309-324.

Habermas, J., Lennox, S., & Lennox, F. (1974). The Public Sphere: an Encyclopedia Article (1964). *New German Critique*, 3, 49-55.

Habermas, J. (1987). *The Theory of Communicative Action, Volume 2*. Boston: Beacon Press.

Hall, P.M. (1987). Interactionism and the Study of Social Organisation. *The Sociological Quarterly*, 28(1), 1-22.

Hall, P.M. (1995). The Consequences of Qualitative Analysis for Sociological Theory: Beyond the Microlevel. *The Sociological Quarterly*, 36(2), 397-423.

Hall, P.M. (1997). Meta-Power, Social Organisation, and the Shaping of Social Action. *Symbolic Interaction*, 20(4), 397-418.

Hall, P.M. & McGinty, P.J.W. (2002). Social Organisation across Space and Time: The Policy Process, Mesodomain Analysis, and Breadth of Perspective. In Chew, S, Knottnerus, J.D. *Structure, Culture and History*. Lanham, MD: Rowman and Littlefield.

Ham, C. (1980). Promoting consumer participation: the case for collaboration between community health councils and community physicians. *Community Medicine*, 2, 144-147.

Hammersley, M. (1992) *What's wrong with ethnography?* London: Routledge.

Harris, S.R. (2000). The Social Construction of Equality in Everyday Life. *Human Studies*. 23, 371-393.

Harrison, S., & Mort, M. (1998). Which Champions, Which People? Public and User Involvement in Health Care as a Technology of Legitimation. *Social Policy & Administration*, 60-70.

Harvey, L. (2012). Building an 'Aspiration Nation': David Cameron's Conservative Party Speech 2012. [Blog post]. Retrieved from <http://www.celebyouth.org/building-an-aspiration-nation-david-camerons-conservative-party-speech-2012/>

Haug, C.J., & Gaskins, J.N. (2012). Recruiting and retaining volunteer EMTs: from motivation to practical solutions. *International Journal of Sociology and Social Policy*, 32(3), 197-213.

Hodge, S. (2005). Participation, discourse and power: a case study in service user involvement. *Critical Social Policy*, 25(2), 164-179.

Hollander, J.A., & Gordon, H.R. (2006). The Processes of Social Construction in Talk. *Symbolic Interaction*, 29(2), 183-212.

Hoschild, A.R. (1979). Emotion Work, Feeling Rules, and Social Structure. *The American Journal of Sociology*, 85(3), 551-575.

Hughes, C.E. (1945). Dilemmas and Contradictions of Status. *American Journal of Sociology*, 50(5), 353-359.

Hughes, D. (2012). Participant Observation in Health Research. In M. Saks & J. Allsop (Eds), *Qualitative Quantitative and Mixed Methods*. 2nd edition (pp. 106-127). London: Sage.

Hughes, D., & Vincent-Jones, P. (2008). Schism in the Church: National Health Service Systems and Institutional Divergence in

England and Wales. *Journal of Health and Social Behaviour*, 49, 400-416.

Hughes, D., Mullen, C., & Vincent-Jones, P. (2009). Choice versus voice? PPI policies and the repositioning of the state in England and Wales. *Health Expectations*, 12(3), 237-250.

Hupe, P., & Hill, M. (2007). Street-level bureaucracy and public accountability. *Public Administration*, 85(2), 279-299.

Jordan, B. (2005). New Labour: Choice and Values. *Critical Social Policy*, 25(4), 427-446.

Kahn, S., & Jerolmack, C. (2013). Saying meritocracy and doing privilege. *The Sociological Quarterly*, 54, 9-19.

Kato, Y. (2011). Coming of age in the bubble: suburban adolescents' use of a spatial metaphor as a symbolic boundary. *Symbolic Interaction*, 34(2), 244-264.

Kitchin, R. (1998). 'Out of Place', 'Knowing One's Place': space, power and the exclusion of disabled people. *Disability & Society*, 13(3), 343-356.

Klein, R., & Lewis, J. (1976). *The politics of consumer representation: A study of Community Health Councils*. London: Centre for Studies in Social Policy.

Learmonth, M., Graham, P.M., & Warwick, P. (2009). Ordinary and effective: the Catch-22 in managing the public voice in health care? *Health Expectations*, 12, 106-115.

Lindsey, R., & Bulloch, S.L. (2013). *What the public think of the 'Big Society': Mass Observers' views on individual and community capacity for civic engagement. Working Paper 95.* Third Sector Research Centre.

Lehoux, P., Daudelin, G., & Abelson, J. (2012). The unbearable lightness of citizens within public deliberation processes. *Social Science and Medicine*, 74, 1843-1850.

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J., & Morgan, K. (2002). 'The public is too subjective': public involvement at different levels of health-care decision making. *Social Science and Medicine*, 54, 1825-1837.

Loe, M., & Cuttino, L. (2008). Grappling with the Medicated Self: The Case of ADHD College Student. *Symbolic Interaction*, 31(3), 303-323.

Lofland, J. (1970). Interactionist imagery and analytic interrupt. In Shibutani, T. (Ed), *Human Nature and Collective Behavior: Papers in Honour of Herbert Blumer*. Englewood Cliffs, NJ: Prentice Hall.

Loh, A., Simon, D., Bieber, C., Eich, W., & Härter, M. (2007). Patient and citizen participation in German health care – current state and future perspectives. *German Journal for Quality in Health Care*, 101(4), 229-235.

Lorenz, L.S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations*, 12, 262-274.

MacCannell, D. (1973). Staged Authenticity: Arrangements of Social Space in Tourist Settings. *American Journal of Sociology*, 79(3), 589-603.

Mackenzie, M., Reid, M., Turner, F., Wang, Y., Clarke, J., Sridharan, S., Platt, S., & O'Donnell, C. (2012). Reaching the Hard-to-Reach: Conceptual Puzzles and Challenges for Policy and Practice. *Journal of Social Policy*, 41(3), 511-532.

Maines, D. (1977). Social Organisation and Social Structure in Symbolic Interactionist Thought. *Annual Review of Sociology*, 3, 235-259.

Maines, D. (1982). In Search of Mesostructure: Studies in the Negotiated Order. *Urban Life*, 11(3), 267-279.

Maines, D.R. (1988). Myth, Text, and Interactionist Complicity in the Neglect of Blumer's Macrosociology. *Symbolic Interaction*, 11(1), 43-57.

Maines, D. (2001). *The Faultline of Consciousness: a View of Interactionism in Sociology*. New York: Aldine de Gruyter.

McGinty, P.J.W. (2014). Divided and Drifting: Interactionism and the Neglect of Social Organisational Analyses in Organisation Studies. *Symbolic Interaction*, 37(2), 155-186.

Martin, G.P. (2008). 'Ordinary people only': knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness*, 30(1), 35-54.

Martin, G.P. (2008). Representativeness, legitimacy and power in public involvement in health-service management. *Social Science & Medicine*, 67(11), 1757-1765.

Martin, G.P. (2009). Public and user participation in public service delivery: tensions in policy and practice. *Sociology Compass*, 3(2), 310-326.

Martin, G.P., & Finn, R. (2011). Patients as team members: opportunities, challenges and paradoxes of including patients in multi-professional healthcare teams. *Sociology of Health and Illness*, 33(7), 1050-1065.

Matza, D. (1969). *Becoming Deviant*. Englewood Cliffs, NJ: Prentice-Hall.

Mead, G.H. (1934). *Mind, Self, and Society: From the Standpoint of a Social Behaviorist*. Chicago: The University of Chicago Press.

Milligan, M.J. (1998). Interactional Past and Potential: The Social Construction of Place Attachment. *Symbolic Interaction*, 21(1), 1-33.

Miller, G. (1997). Contextualizing Texts: Studying Organisational Texts. In G. Miller & R. Dingwall (Eds), *Context and Method in Qualitative Research* (pp. 77-91). London: Sage.

Miller, G. (1997). Towards ethnographies of institutional discourse: proposal and suggestions. In G. Miller & R. Dingwall (Eds), *Context and Method in Qualitative Research* (pp. 155-171). London: Sage.

Mullen, C., Hughes, D., & Vincent-Jones, P. (2011). The Democratic Potential of Public Participation: Healthcare Governance in England. *Social Legal Studies*, 20(1), 21-38.

Murphy, E., & Dingwall, R. (2003). *Qualitative Methods and Health Policy Research*. New York: Aldine De Gruyter.

Nadai, E., & Maeder, C. (2008). Negotiations at all points? Interaction and organisation. *Forum: Qualitative Social Research*, 9(1), Art. 32. Retrievable from <http://www.qualitative-research.net/index.php/fqs/article/view/337/736>

Nelsen, B.J., & Barley, S.R. (1997). For Love or Money? Commodification and the Construction of an Occupational Mandate. *Administrative Science Quarterly*, 42(4), 619-653.

NHS Centre for Involvement (2008). *Local Involvement Networks. Guide No. 1 Summary. Local Government and Public Involvement in Health Act 2007*. NHS Centre for Involvement.

NHS Centre for Involvement (2008). *Local Involvement Networks. Guide No. 5 Procuring a Host*. NHS Centre for Involvement. Retrievable from <http://www.lx.nhs.uk/resources/adviceandguidance/?id=18&start2=10&order=title>

NHS Centre for Involvement (2008). *Making people aware of Local Involvement Networks. Guide No. 8* NHS Centre for Involvement.

NHS Centre for Involvement (2008). *Local Involvement Networks. Guide No. 12 Governance*. NHS Centre for Involvement.

NHS Centre for Involvement (2008). *Local Involvement Networks. Guide No. 11 Accountability and Transparency*. NHS Centre for Involvement.

NHS Centre for Involvement (2008). *Local Involvement Networks. Guide No. 16 Community Development*. NHS Centre for Involvement.

NHS Confederation. (2011). *Patient and public engagement in the new commissioning system: a discussion paper*. Retrieved from the NHS Confederation website:
<http://www.nhsconfed.org/Publications/discussion-paper/Pages/PPE.aspx>

NHS Future Forum. (2011). *Patient Involvement and Public Accountability: a report from the NHS Future Forum*. Retrieved from the UK Government website:
<https://www.gov.uk/government/publications/nhs-future-forum-recommendations-to-government-on-nhs-modernisation>

NHS National Services Scotland (2010). NHS National Services Scotland. Patient Focus Public Involvement Summary Report 2009/2010. Retrieved from
http://www.nhsnss.org/supplementary_pages/publication_detail.php?id=117

O'Keefe, E., & Hogg, C (1999). Public participation and marginalised groups: the community development model. *Health Expectations*, 2, 245-254.

Oakley, J. (2002). Thinking through Fieldwork. In A. Bryman & R.G. Burgess (Eds), *Analysing Qualitative Data* (pp. 18-34). London: Routledge.

Oliver, S.R., Rees, R.W., Clarke-Jones, L., Milne, R., Oakley, A. R., Gabbay, J., Stein, K., Buchanan, P., & Gyte, G. (2008). A multidimensional conceptual framework for analysing public

involvement in health services research. *Health Expectations*, 11(1), 72-84.

Oldham, J. (1979). Social Control of Voluntary Work Activity: The Gift Horse Syndrome. *Work and Occupations*, 6(4), 379-403.

O'Toole, R., & O'Toole, A.W. (1981). Negotiating Inter-organisational Orders. *The Sociological Quarterly*, 22(1), 29-41.

Paap, W.R., & Hanson, B. (1982). Unobtrusive Power: Interaction Between Health Providers and Consumers at Council Meetings. *Journal of Contemporary Ethnography*, 10(4), 409-431.

Pickard, S. (1997). The Future Organisation of Community Health Councils. *Social Policy & Administration*, 31(3), 274-289.

Plummer, K. (2000). A World in the Making: Symbolic Interactionism in the Twentieth Century. In B.S. Turner (Ed), *The Blackwell Companion to Social Theory. Second Edition* (pp. 193-222). Wiley-Blackwell. Retrieved from <http://kenplummer.com/publications/selected-writings-2/humanism-and-symbolic-interactionism/>

Plummer, K. (2003). Continuity and Change in Howard S. Becker's Work. An Interview with Howard S. Becker. *Sociological Perspectives*, 46(1), 21-39.

Polsky, N. (1967). *Hustlers, Beats, and Others*. Chicago: Aldine Publishing Company.

Pope, C. (2005). Conducting ethnography in medical settings. *Medical Education*, 39, 1180-1187.

Potter, D.A. (2010). 'Wrong parents' and 'right parents': shared perspectives about citizen participation in policy implementation. *Social Science & Medicine*, 70(11), 1705-1713.

Prior, L. (2004). Doing things with documents. In D. Silverman (Ed.), *Qualitative Research. Theory, Method and Practice*. 2nd edition (pp. 76-94). London: Sage.

Prus, R. (1987). Ethnographic Research in Process: A Reply to Professor Robboy. *Journal of Contemporary Ethnography*, 16(3), 301-307.

Prus, R. (1987). Generic Social Processes: Maximizing Conceptual Development in Ethnographic Research. *Journal of Contemporary Ethnography*, 16(3), 250-293.

Prus, R. (2003). Policy as a Collective Venture: A Symbolic Interactionist Approach to the Study of Organisational Directives. *International Journal of Sociology and Social Policy*, 23(6/7), 13-60.

Prus, R. (2004). Symbolic Interaction and Classical Greek Scholarship: Conceptual Foundations, Historical Continuities, and Transcontextual Relevancies. *The American Sociologist*, 35(1), 5-33.

Prus, R. (2007). On Studying Ethnologists (Not Just People, Societies in Miniature): The Necessities of Ethnography, History, and Comparative Analysis. *Journal of Contemporary Ethnography*, 36(6), 669-703.

Prus, P. (2008). Authenticity, activity, and conceptuality: generating a pluralist, humanist, and enduring social science. In N. Denzin, J. Salvo, & M. Washington (Eds) *Studies in Symbolic Interaction*. Volume 32 (pp. 19-36). Emerald Group Publishing Limited.

Health and Social Care Public Health Agency. (2012). *Valuing People, Valuing Their Participation. A Strategy for Personal and Public Involvement for the Public Health Agency and Health and Social Care Board*. Retrieved from <http://www.publichealth.hscni.net/publications/valuing-people-valuing-their-participation-strategy-personal-and-public-involvement-pub>

Renedo, A., & Marston, C. (2011). Healthcare Professionals' Representations of 'Patient and Public Involvement' and Creation of 'Public Participant' Identities: Implications for the Development of Inclusive and Bottom-up Community Participation Initiatives. *Journal of Community & Applied Social Psychology*, 21, 268-280.

Rhodes, P., & Nocon, A. (1998). User involvement and the NHS reforms. *Health Expectations*, 1(2), 73-81.

Rock, P. (2001). Symbolic Interactionism and Ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, L. Lofland (Eds) *Handbook of Ethnography* (pp. 26-38). London: Sage Publications.

Rowe, R., & Shepherd, M. (2002). Public Participation in the New NHS: No Closer to Citizen Control? *Social Policy & Administration*, 36(3), 275-290.

Rowe, G., & Frewer, L.J. (2005). A Typology of Public Engagement Mechanisms. *Science, Technology and Human Values*, 30(2), 251-290.

Rutter, D., Manley, C., Weaver, T., Crawford, M.J., & Fulop, N. (2004). Patients or Partners? Case studies of user involvement in the

planning and delivery of adult mental health services in London. *Social Science and Medicine*, 58, 1973-1984.

Sabatier, P.A. (1986). Top-down and Bottom-up Approaches to Implementation Research: a Critical Analysis and Suggested Synthesis. *Journal of Public Policy*, 6, 21-48.

Salazar, C., & Orobittg, G. (2011). The making of an imagined community: The press as a mediator in ethnographic research into Assisted Reproductive Technologies (ART). *Ethnography*, 13(2), 236-255.

Sandstrom, K.L., Martin, D.D., & Fine, G.A. (2001). Symbolic Interactionism at the end of the Century. In Ritzer, G. & Smart, B. (Eds) *Handbook of Social Theory* (pp. 217-32). London: Sage.

Schofield, J. (2001). Time for a revival? Public policy implementation: a review of the literature and an agenda for future research. *International Journal of Management Reviews*, 3(3), 245-263.

Schwartz, B. (1974). Waiting, Exchange, and Power: The Distribution of Time in Social Systems. *American Journal of Sociology*, 79(4), 841-870.

Seale, C. (1999). Quality in Qualitative Research. *Qualitative Inquiry*, 5(4), 465-478.

Serapioni, M., & Duxbury, N. (2012). Citizen's participation in the Italian health-care system: the experience of the Mixed Advisory Committees. *Health Expectations*. doi: 10.1111/j.1369-7625.2012.00775.x

Shaw, S., Elston, J., & Abbott, S. (2004). Comparative analysis of health policy implementation: The use of documentary analysis. *Policy Studies, 25*(4), 259-266.

Silverman, D. (1998). Qualitative research: meanings or practices? *Information Systems Journal, 8*(1), 3-20.

Smith, R.S. (1999). Contested Memory: Notes in Robert K. Merton's "The Thomas Theorem and the Matthew Effect". *The American Sociologist, 30*(2), 62-77.

Smith, R.W., & Bugni, V. (2006). Symbolic Interaction Theory and Architecture. *Symbolic Interaction, 29*(2), 123-155.

Spradley, J.P. (1980). *Participant Observation*. New York: Holt, Rinehard and Winston.

Stake, R. E. (1978). The Case Study Method in Social Inquiry. *Educational Researcher, 7*(2), 5-8.

Staniszewska, S., Herron-Marx, S. & Mockford, C. (2008). Measuring the impact of patient and public involvement: the need for an evidence base. *International Journal for Quality in Health Care, 20*(6), 373-374.

Starbuck, W. (1982). Congealing oil: Inventing ideologies to justify acting ideologies out. *Journal of Management Studies, 19*, 1-27.

Stevens, F.C.J. (2014). Negotiated Orders. In Cockerham, W.C., Dingwall, R., & Quah, S.R. (Eds) *The Wiley-Blackwell Encyclopedia of Health, Illness, Behavior and Society, First Edition*. New York: John Wiley & Sons, Ltd.

Stewart, E. (2013). A mutual NHS? The emergence of distinctive public involvement policy in a devolved Scotland. *Policy & Politics*, 41(2), 241-258.

Stolte, J.F., Fine, G.A., & Cook, K.S. (2001). Sociological miniaturism: Seeing the Big through the Small in Social Psychology. *Annual Review of Sociology*, 27, 387-413.

Strauss, A.L. (1978). *Negotiations: Varieties, Contexts, Processes, and Social Order*. San Francisco: Jossey Bass Publishers.

Strauss, A.L., Schatzman, L., Bucher, R., Ehrlich, D., & Sabshin, M. (1964). *Psychiatric Ideologies and Institutions*. New York: Free Press.

Strong, P.M., & Dingwall, R. (1983). The limits of negotiation in formal organisations. In G.N. Gilbert & P. Abell (Eds) *Accounts and Actions*. Farnborough: Gower.

Strong, P.M., & Dingwall, R. (1989). Romantics and stoics. In Gubrium, J. & Silverman, D. (Eds) *The Politics of Field Research: Sociology Beyond Enlightenment*. London: Sage.

Sudnow, D. (1967). *Passing On. The Social Organization of Dying*. Englewood Cliffs, NJ: Prentice-Hall.

Tardy, R.W. (2000). "But I am a Good Mom": The Social Construction of Motherhood through Health-Care Conversations. *Journal of Contemporary Ethnography*, 29(4), 433-473.

Teubner, G. (Ed) (1987) *Juridification of Social Spheres: A Comparative Analysis in the Areas of Labor, Corporate, Antitrust and Social Welfare Law*. Berlin/New York: Walter de Gruyter.

The Welsh NHS Confederation. *Key area: Citizen Engagement and Involvement*, from <http://www.welshnhsboarddevelopment.org/CitizenEngagement.htm>

Tritter, J.Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2), 156-168.

Tritter, J.Q., & Luftey, K. (2009). Bridging divides: patient and public involvement on both sides of the Atlantic. *Health Expectations*, 12(3), 221-225.

Tritter, J.Q. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*, 12(3), 275-287.

Tritter, J.Q. (2011). Public and patient participation in health care and health policy in the United Kingdom. *Health Expectations*, 14, 220-223.

Tritter, J.Q., & Koivusalo, M. (2013). Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement. *Health Expectations*, 16, 115-118.

Van de Bovenkamp, H., & Trappenburg, M.J. (2009). Patient participation in collective healthcare decision making: the Dutch model. *Health Expectations*, 12, 73-85.

Vertovec, S. (2007). Super-diversity and its implications. *Ethnic and Racial Studies*, 30(6), 1024-1054.

Vincent-Jones, P., Hughes, D., & Mullen, C. (2009). New Labour's PPI Reforms: Patient and Public Involvement in Healthcare Governance? *The Modern Law Review*, 72(2), 247-271.

Wait, S., & Nolte, E. (2006). Public involvement policies in health: exploring their conceptual basis. *Health Economics, Policy & Law*, 1(2), 149-162.

Walsh, J.P., & Ungson, G.R. (1991). Organisational memory. *Academy of Management Review*, 16(1), 57-91.

Warner, M. (2002). Publics and Counterpublics (abbreviated version). *Quarterly Journal of Speech*, 88(4), 413-425.

Weiner, K. (2009). Lay involvement and Legitimacy – The Construction of Expertise and Participation within HEART UK. *Journal of Contemporary Ethnography*, 38(2), 254-273.

Wellman, D. (1988). The Politics of Herbert Blumer's Sociological Method. *Symbolic Interaction*, 11(1), 59-68.

Wells, P. (2007). New Labour and evidence based policy making. *People, Place & Policy Online*, 1(1), 21-29. doi: 10.3351/ppp.0001.0001.0004

Welsh Assembly Government (2004). *Making the Connections – Delivering Better Services for Wales. The Welsh Assembly Government vision for public services*. Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2005). *Designed for Life: Creating world class Health and Social Care for Wales in the 21st Century*. Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2006). *Review of Local Service Delivery: Report to the Welsh Assembly Government. Beyond Boundaries. Citizen-centred Local Services for Wales*. Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2008). *Consultation Paper on Proposals to Change the Structure of the NHS in Wales*. Cardiff: Welsh Assembly Government.

Welsh Assembly Government (2009). *Welsh Assembly Government's Single Equality Scheme. Executive Summary 2009-2012*. Cardiff: Welsh Assembly Government.

Welsh Government (2011). *Information for candidates, Community Health Council Appointment of Members*. Retrieved from <http://tinyurl.com/pa8h9ul>

Welsh Government (2011). *Guidance for Engagement and Consultation on Changes to Health Services*. Cardiff: Welsh Assembly Government.

Welsh Government (2012). Local Service Boards. Retrieved from <http://wales.gov.uk/topics/improvingservices/localserviceboards/?lang=en>

Wharton, C.S. (1991). Why can't we be friends? Expectations versus Experiences in the Volunteer Role. *Journal of Contemporary Ethnography*, 20(1), 79-106.

Whyte, W.F. (1993). *Street Corner Society. The Social Structure of an Italian Slum. 4th edition.* The University of Chicago Press.

Williams, G.R. (2009). *Hospital Patient Environment, External Assessment Visit, Annual Report 2009.* Cardiff: Board of Community Health Councils in Wales.

Williams, M. (2004). Discursive Democracy and New Labour: Five Ways in Which Decision-Makers Manage Citizen Agendas in Public Participation Initiatives. *Sociological Research Online*, 9(3).

Wittenberg, D. (2002). Going Out in Public: Visibility and Anonymity in Michael Warners' "Public and Counterpublics". *Quarterly Journal of Speech*, 88(4), 426-433.

Yin, R. K. (1999). Enhancing the Quality of Case Studies in Health Services Research. *Health Services Research*, 34(5), 1209-1224.

Yin, R.K. (2009). *Case Study Research: Design and Method. 4th Edition.* Sage Publications.

Yin, R.K. (2011). *Applications of Case Study Research.* Sage Publications.

Young, R. (2006). Introducing Role and Service Changes in Health and Social Care: The Impact and Influence of User Involvement in England and Wales. *Social Policy & Society*, 5(2), 249-268.

APPENDIX ONE: TABLE WITH PARTICIPANTS' PSEUDONYMS

Informants in Greenshire	Role
Ken	Volunteer
Emma	Volunteer
Luke	Volunteer
Lucy	Volunteer
Gary	Volunteer
Kirsty	Volunteer
Tyler	Volunteer
Rachel	Volunteer
Beth	Development worker
James	LA officer
Kate	NHS professional
Informants in Red City	Role
Andy	Volunteer
Michael	Volunteer
Sheila	Volunteer
Charlie	Volunteer
Paul	Volunteer
Tanya	Volunteer
Daniel	Volunteer
Harriet	Volunteer
Sebastian	Volunteer
Chantal	Development worker
Nadine	Communication and publicity officer
Amy	Research officer
Helen	Development worker
Joyce	Host organisation's manager
Arthur	NHS professional
Charlotte	NHS professional
Informants in Rainbow City	Role
Rhys	Member
Stella	Member
Janice	Member
Ian	Member
Pauline	Member
Max	Member
Sally	Member
Abi	Member
Danielle	Member

Chris	Member
Alexandra	PA to the CO
Simon	CO
Marie	PPE officer
Joey	Primary Care and Patient Involvement officer; deputy CO and CO
Fiona	NHS professional
David	NHS professional
Informants in Blue City	Role
Ray	Member
Ryan	Member
Eden	Member
Carrie	Member
Ray	Member
Gabriel	Member
Rose	Member
Anne	Member
Amber	Member
Norma	Member
Mel	Member
Esther	PA; PPE officer
Leanne	CO
Ed	CO; Deputy CO
Dexter	CO
Leigh	NHS professional

APPENDIX TWO: INFORMATION SHEET

Information about the Research

Constructing the meanings of Patient and Public Involvement (PPI) within local organisations: a study in Wales and England

Principal investigator: Silvia Scalabrini

Institution: Swansea University

Introduction: I am a full-time PhD candidate based in the School of Human and Health Sciences and I am a mature student with some experience of PPI research. My two supervisors are Professor David Hughes (School of Health and Human Sciences) and Dr David Rea who is co- Associate Director of *Involving People*.

Summary: The study will investigate similarities and differences in understandings of PPI in England and Wales. The focus is on Welsh Community Health Councils and English Local Involvement Networks and their related organisations as sites for exploring patient, public and agency staff's perspectives on involvement and what it means.

Purpose of the study: The main purpose of the research project is to investigate the process of constructing the meaning of PPI activities within local organisations/networks in England and Wales. This will be achieved through a study to be carried out in two Welsh Community Health Councils and in two English Local Involvement Networks.

Why have I been chosen? You have been contacted either because you are a regular participant in the meetings of your local organisation or because you have been identified by other people as a key actor in the local PPI arena.

Do I have to take part? Your participation is voluntary and you can decline to take part. If you agree to participate in the study, you will be asked to sign a consent form and you will be interviewed for about one hour. It will therefore take some of your time, but I will endeavour to arrange a time and place suitable for you. Even if you agree to help us, you are free to withdraw from the study at any time. You may also ask me (at a later stage) to disregard certain things that you said in the interview and this information will then not be included in the analysis.

Are there any risks? There are no physical risks in taking part in this research. I give my firm assurance that you and your organisation will not be put at risk by any voluntary disclosure of confidential information to third parties. There have been cases in recent years where researchers have been required to make research data available to the courts after legal action has been taken. I cannot give an absolute guarantee that this will not happen in the present study, but in my judgement this is very unlikely to occur given the subject matter of the research.

What about confidentiality? Your name and identity will not be disclosed at any time. Confidentiality will be assured in the following ways: all information will be fully anonymised so that nobody can identify you from any extracts from the interview that we may use in reports. The tape recordings of interviews will be fully transcribed and stored in locked cabinets in the School of Human and Health Science at Swansea University. Then audio files will be deleted. I will adhere fully to the Data Protection Act 1998 at all times.

What will happen to the results of the research study? The results of the study will be part of my PhD thesis, which should be completed by the end of 2013. Anonymised findings of the study may also appear in academic publications.

Contact for further information:

If you would like to discuss any aspect of the study, if you have any concerns or questions, please feel free to contact me either on my mobile number [REDACTED] or on my email address [REDACTED]

Thank you for taking the time to read this information sheet.

APPENDIX THREE: CONSENT FORM

CONSENT FORM

Title of the study: Constructing the meanings of Patient and Public Involvement (PPI) within local organisations: a study in England and Wales.

Your participation consists of one interview, lasting approximately one hour, where you will be asked a series of questions about your role in relation to local organisations concerned with patient and public involvement (PPI), your views about PPI activities and your perspectives regarding the general implementation of PPI strategies.

Please initial box

I confirm that I have read and understand the information sheet for the above study. I have had an opportunity to consider the information, ask questions about the study and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
I understand that the interview that I take part in will be audio-taped and fully transcribed.	
I understand that the researcher will keep my identity confidential and that all the information I will provide will be used only for the purpose of the research.	

I agree to participate in the study above.

Name of Participant:	
Signature:	Date:

Name of Investigator:	
Signature:	Date:

APPENDIX FOUR: ETHICAL ISSUES

Dear David

Thank you for speaking with me a moment ago with regard to this study.

Having talked through the attached "Defining Research" leaflet, I am happy to confirm that this piece of work would not fall into the category of research by its definitions, but rather would be service evaluation. This would not require ethical review.

Kind regards

Dr Corinne Scott (Wales REC Manager), email sent on November 23, 2009

Hi David/Silvia

As Corinne has given a clear indication that the NHS MREC sees this as service evaluation an application to the School Research Ethics committee will be fine. Deb Fitzsimmons signs off on governance issues for PhD students so it may be worth Silvia talking to Deb in the first place regarding what the process is with regard to getting this sorted. I'm more than happy to discuss the School's ethics form etc when Silvia is ready to progress with this.

Dr Aled Jones (Chair of the College of Human and Health Sciences REC), email sent on November 24, 2009

Dear Silvia

Thanks for your application for research ethics approval. The committee have approved your application in principle, however we do require some further information and clarification before we can confirm approval. The issues we would like you to address are:

1. The information letter for those being recruited into the interview study – could you please clarify for the participants what the acronym PPI stands for.
2. Is the telephone number at the end of the letter your personal mobile telephone or is it a phone that will be used just for this study? We usually recommend that researchers do not share their personal mobile telephone interviews.

The committee have decided that I can take Chair's action to approve the study once the above points have been attended to. This means that a full re-application to the next committee meeting isn't required and that I can approve the decision once I am

satisfied with the changes. There is also no need to amend the application form, you can just email me changes, although I would like to see changes made to information letter where appropriate.

I'm happy to discuss point 2 above with you when you return following your holiday.

Regards,
DrAled Jones, email sent on January 5, 2010

Hi Silvia

Thanks for forwarding the changes to your application, I am now able to approve your study and wish you all the best with your project.

Regards
Dr Aled Jones, email sent on January 12, 2010