

# ULRR

## Community participation in action: involving communities in primary care teams

|               |   |
|---------------|---|
| Item Type     | Thesis  |
| Authors       | Tierney, Edel   |
| Download date | 2026-06-06 17:35:44   |
| Item License  | <a href="https://creativecommons.org/licenses/by-nc-sa/1.0/">https://creativecommons.org/licenses/by-nc-sa/1.0/</a> |
| Link to Item  | <a href="https://hdl.handle.net/10344/8153">https://hdl.handle.net/10344/8153</a>                                   |



**UNIVERSITY of LIMERICK**

OLLSCOIL LUIMNIGH

**“Community Participation in Action:  
Involving Communities in Primary Care  
Teams”**

Edel Tierney

PhD (Medicine – Primary Care)

Student number 14211696

University of Limerick

Supervisors: Professor Anne MacFarlane and Professor Ailish  
Hannigan

Submitted to the University of Limerick

May 2019



**Dedication**  
**This thesis is dedicated to my Dad**  
**Who taught me all I know about digging deep**

**Digging<sup>1</sup>**

By Seamus Heaney

Between my finger and my thumb  
The squat pen rests; snug as a gun.

Under my window, a clean rasping sound  
When the spade sinks into gravelly ground:  
My father, digging. I look down

Till his straining rump among the flowerbeds  
Bends low, comes up twenty years away  
Stooping in rhythm through potato drills  
Where he was digging.

The coarse boot nestled on the lug, the shaft  
Against the inside knee was levered firmly.  
He rooted out tall tops, buried the bright edge deep  
To scatter new potatoes that we picked,  
Loving their cool hardness in our hands.

By God, the old man could handle a spade.  
Just like his old man.

My grandfather cut more turf in a day  
Than any other man on Toner's bog.  
Once I carried him milk in a bottle  
Corked sloppily with paper. He straightened up  
To drink it, then fell to right away  
Nicking and slicing neatly, heaving sods  
Over his shoulder, going down and down  
For the good turf. Digging.

The cold smell of potato mould, the squelch and slap  
Of soggy peat, the curt cuts of an edge  
Through living roots awaken in my head.  
But I've no spade to follow men like them.

Between my finger and my thumb  
The squat pen rests.  
I'll dig with it.

---

<sup>1</sup> Seamus Heaney, "Digging" from *Death of a Naturalist*. Copyright 1966 by Seamus Heaney. Reprinted with the permission of. Permissions Department Faber & Faber Ltd:

## **Abstract**

**Background:** The concept of involving communities in healthcare planning is enshrined in health policy across international settings. There is evidence of community participation impacting positively on health services. However, despite this policy context, there are major gaps in our knowledge. It is not routine across all primary health care settings and there is a lack of theoretically informed studies about implementation of community participation on interdisciplinary teams. This theoretically informed study draws on three inter-related projects to explore the perspectives of various stakeholders implementing community participation on primary care teams (PCTs) in Ireland.

**Method:** Based on the pragmatic paradigm and principles of participatory qualitative health research, a case study approach was adopted using a sequential exploratory mixed methods design underpinned by Normalisation Process Theory (NPT). Participants represented health care professionals, GPs, community representatives, patients from marginalised groups and health service planners and policy makers from across a variety of primary health care settings. Data analysis took place at two levels– individual study level and data integration level and was informed by NPT constructs.

**Findings:** Levers to implementation of community participation on PCTs included a shared understanding among stakeholders of the value of the work and good relationships and champions who support community initiatives. Barriers included a lack of resources for PCTs, complex health care structures, mistrust among team members and lack of formal appraisal of outcomes.

**Conclusion:** It is a challenge to sustain community participation on PCTs in an environment where PCTs are struggling to be established. Overall, the lack of universal coherence about the work and poor implementation of PCTs impacts buy in, enactment and appraisals of the work thereby making implementation challenging and sustainability unlikely. The data about levers and barriers reported are important because they provide clear information about activities, processes and relationships that can support implementation.

## **Declaration**

The work is submitted to fulfil the requirements of the degree of Doctor of Philosophy at the University of Limerick. Three of the papers presented (i.e., Chapters 4-6) have been previously published in peer reviewed journals. The PhD candidate's contribution to the papers comprising the thesis is outlined in Chapter 1 of this thesis.

Apart from due acknowledgements, this is entirely my own work.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

## **Acknowledgements**

I wish to extend my deepest gratitude to my two supervisors Professor Anne MacFarlane and Professor Ailish Hannigan for their constant guidance and support during my four years registered as a PhD student. I am eternally grateful for their words of wisdom, insight, inspiration and encouragement which helped keep this thesis on track.

To my colleagues at University of Limerick and NUI Galway for their help and support throughout this journey. It was a gift to have your listening ears and PhD experiences especially in the last leg of this thesis. Especially to, Dr Ruth McMenamin, Dr Rachel McEvoy, Dr Mary O'Reilly de Brún, Dr Tomas de Brún, Dr Patrick O'Donnell, Madeleine O'Sullivan and Brendan Dolan. For your encouragement, friendship and inspiration not to mention the copious cups of coffee which made this journey a bit smoother.

Sincere thank you to the Graduate Entry Medical School who funded the fees for this PhD.

I wish to acknowledge the experience and expertise of all my co-authors on the three papers reprinted in this thesis who provided much valuable input throughout this research. The publication journey was made smoother by your input.

To all those communities, primary care team members and organisations around the country who strive to empower people on the margins of society and who support participation in primary healthcare. I hope this study will contribute to a greater appreciation of your work and understanding about the impact it has on people's

lives. Thank you for the work you do to empower people and your endeavours to make our communities and health services more person centred.

Most especially to the participants involved in the three studies comprising this PhD.

I am deeply indebted to you for sharing your experiences and your lived expertise about this area. Without you, there is no community participation and no PhD thesis!

To my father Michael and to my family, I am fortunate enough to say there are too many family members old and young to name. In my father's words, '*Everything comes right in its own good time*'. To Mollie and Lucy Eile (RIP) for your constant companionship and for reminding me of the other beings in the world (who do not appreciate the time a PhD takes from other more worthwhile activities!)

Finally, to friendship and to all of my friends who have been there through this shared adventure. I am lucky to count all of you as my friends. You know who you are! You have supported me in so many ways on this PhD and life journey....and have shown me that there is more.... much more.

## Table of Contents

|  |           |
|--|-----------|
| <b>Dedication</b>  | <b>2</b>  |
| <b>Abstract</b>  | <b>3</b>  |
| <b>Declaration</b>   | <b>5</b>  |
| <b>Acknowledgements</b>  | <b>6</b>  |
| <b>Abbreviations</b>   | <b>18</b> |
| <b>List of Publications</b>  | <b>19</b> |
| <b>Chapter 1: Introduction</b>   | <b>20</b> |
| 1.1 International and national policy context for community participation in primary healthcare.....                                       | 20        |
| 1.2 Rationale for this study .....   | 24        |
| 1.3 Researcher Role and Contribution to the Research.....  | 25        |
| 1.4 Research Aims and Objectives .....   | 32        |
| 1.5 Participants/Stakeholders .....  | 32        |
| 1.6 Theory underpinning this PhD .....   | 33        |
| 1.7 Thesis Outline .....   | 34        |
| 1.8 Summary .....  | 35        |
| 1.9 References .....   | 36        |
| <b>Chapter 2: Community Participation in Primary Health Care - the Literature</b>  | <b>39</b> |
| 2.1 Introduction .....   | 39        |
| 2.2 Concepts of community participation in primary health care, frameworks and appraisal of outcomes .....                                 | 40        |
| 2.2.1 Conceptualisation of community participation .....   | 42        |
| 2.2.2 Frameworks describing community participation in primary health care   | 44        |
| 2.2.3 Appraising community participation in primary health care; evidence of impact of community participation on primary health care..... | 47        |
| 2.3 Operationalisation of community participation in western democracies.....  | 50        |
| 2.3.1 Collective participation and deliberative democracy methods .....  | 51        |
| 2.3.3 Implementing community participation in primary health care.....   | 61        |
| 2.3.4 Community participation with marginalised groups.....  | 63        |

|       |  |            |
|-------|--|------------|
| 2.4   | Policy Research, Implementation theory and Normalisation Process Theory (NPT) as an underpinning theory.....   | 64         |
| 2.4.1 | Health Policy and Health Policy and Systems Research: .....  | 65         |
| 2.4.2 | Implementation research to explore HPSR .....  | 66         |
| 2.4.3 | Theory in Implementation Research .....  | 66         |
| 2.4.4 | NPT as implementation theory underpinning this PhD .....   | 67         |
| 2.5   | Summary of the Literature .....  | 68         |
| 2.6   | References .....   | 69         |
|       | <b>Chapter 3: Methodology.....</b>   | <b>88</b>  |
| 3.1   | Introduction .....   | 88         |
| 3.2   | Part 1 Introduction: Ontology, Epistemology and Methodological Approach ..   | 88         |
| 3.2.1 | Other paradigmatic influences in this PhD .....  | 93         |
| 3.3   | Ethical considerations across the three projects.....  | 96         |
| 3.4   | Research Design: Case Study Approach.....  | 97         |
| 3.4.1 | Critique of a case study approach .....  | 103        |
| 3.4.2 | Research Design: Mixed Methods .....   | 106        |
| 3.5   | Theoretical Foundation of this PhD: Normalisation Process Theory .....   | 108        |
| 3.6   | Approach to integrated data analysis using NPT .....   | 112        |
| 3.7   | Summary .....  | 115        |
| 3.8   | References .....   | 117        |
|       | <b>Chapter 4 Paper 1: Do primary care professionals agree about progress with implementation of Primary Care Teams: – Results from a cross sectional study .....</b> | <b>123</b> |
| 4.1   | Abstract .....   | 123        |
| 4.2   | Background .....   | 125        |
| 4.3   | Methods .....  | 128        |
| 4.3.1 | Study Context.....   | 128        |
| 4.3.2 | Participants.....  | 129        |
| 4.3.3 | Survey design.....   | 129        |
| 4.3.4 | Sampling method .....  | 131        |
| 4.3.5 | Statistical methods .....  | 132        |
| 4.4   | Results .....  | 132        |
| 4.4.1 | Response Rate .....  | 132        |
| 4.4.2 | Demographics .....   | 134        |

|                   |   |            |
|-------------------|---|------------|
| 4.4.3             | Composition of Primary Care Teams.....  | 136        |
| 4.4.4             | Perceptions of PCT working and progress with PCT implementation in Ireland .....  | 138        |
| 4.4.5             | Requirements for effective PCT working to support its implementation .....  | 141        |
| 4.5               | Discussion .....  | 145        |
| 4.5.1             | Summary .....   | 145        |
| 4.5.2             | Strengths and limitations.....  | 145        |
| 4.5.3             | Comparison with existing literature .....   | 146        |
| 4.5.4             | Implications for research and/or practice .....   | 148        |
| 4.6               | Conclusion .....  | 149        |
| 4.7               | Declarations .....  | 150        |
| 4.7.1             | List of Abbreviations.....  | 150        |
| 4.7.2             | Funding .....   | 150        |
| 4.7.3             | Ethical approval .....  | 150        |
| 4.7.4             | Consent to publish.....   | 151        |
| 4.7.5             | Competing interests.....  | 151        |
| 4.7.6             | Authors Contributions.....  | 151        |
| 4.7.7             | Availability of data and materials .....  | 151        |
| 4.8               | Acknowledgements .....  | 151        |
| 4.9               | Authors' information .....  | 152        |
| 4.10              | Endnotes .....  | 152        |
| 4.11              | References .....  | 152        |
| <b>Chapter 5:</b> | <b>Paper 2: Implementing community participation via interdisciplinary teams in primary care: An Irish case study in practice .....</b> | <b>162</b> |
| 5.1               | Abstract .....  | 162        |
| 5.2               | Introduction .....  | 164        |
| 5.3               | Rationale for this study .....  | 166        |
| 5.4               | Method .....  | 167        |
| 5.4.1             | Study context.....  | 167        |
| 5.4.2             | Study design .....  | 167        |
| 5.4.3             | Sampling and recruitment .....  | 167        |
| 5.5               | Ethical approval .....  | 173        |

|                   |   |            |
|-------------------|---|------------|
| 5.6               | Data generation .....   | 173        |
| 5.7               | Data analysis .....   | 177        |
| 5.7.1             | Quality and rigour .....  | 178        |
| 5.8               | Results .....   | 178        |
| 5.8.1             | Coherence: Can stakeholders make sense of community participation on PCTs as a new way of working? .....  | 181        |
| 5.8.2             | Cognitive participation: Will stakeholders engage with/“buy into” community participation on PCTs? .....  | 183        |
| 5.8.3             | Collective action: What do stakeholders need to enact community participation on PCTs in daily practice? .....  | 185        |
| 5.8.4             | Reflexive monitoring: Can stakeholders formally or informally appraise the impact of community participation on PCTs? .....   | 189        |
| 5.9               | Discussion and conclusions.....   | 193        |
| 5.9.1             | Summary of key findings .....   | 193        |
| 5.9.2             | Methodological critique .....   | 194        |
| 5.9.3             | Comparison with literature.....   | 195        |
| 5.9.4             | Implementation and Enactment.....   | 196        |
| 5.10              | Acknowledgements .....  | 198        |
| 5.11              | References .....  | 198        |
| <b>Chapter 6:</b> | <b>Paper 3: Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study .....</b> | <b>207</b> |
| 6.1               | Abstract .....  | 207        |
| 6.2               | Background .....  | 209        |
| 6.3               | Methods .....   | 211        |
| 6.3.1             | Study setting.....  | 211        |
| 6.3.2             | Research design.....  | 214        |
| 6.3.3             | Sampling and recruitment .....  | 215        |
| 6.3.4             | Research team .....   | 216        |
| 6.3.5             | Data co-generation and co-analysis .....  | 217        |
| 6.3.6             | Thematic analysis.....  | 218        |
| 6.3.7             | Trustworthiness .....   | 219        |
| 6.4               | Results .....   | 220        |
| 6.4.1             | Home.....   | 222        |

|       |  |            |
|-------|--|------------|
| 6.4.2 | ‘Two-Tier’ Healthcare System.....  | 225        |
| 6.4.3 | Healthcare encounters .....  | 229        |
| 6.4.4 | Complex (health) needs.....  | 235        |
| 6.4.5 | Priorities .....   | 241        |
| 6.5   | Discussion .....   | 242        |
| 6.5.1 | Statement of principal findings .....  | 242        |
| 6.5.2 | Discussion of findings in relation to the literature .....   | 243        |
| 6.5.3 | Strengths and weaknesses of the study .....  | 247        |
| 6.5.4 | Clinical and policy implications.....  | 248        |
| 6.5.5 | Areas for further research.....  | 249        |
| 6.6   | Conclusions .....  | 250        |
| 6.7   | List of abbreviations.....   | 250        |
| 6.8   | Declarations .....   | 251        |
| 6.8.1 | Ethics approval and consent to participate.....  | 251        |
| 6.8.2 | Consent for publication .....  | 251        |
| 6.8.3 | Availability of data and material.....   | 251        |
| 6.8.4 | Competing interests.....   | 251        |
| 6.8.5 | Funding .....  | 251        |
| 6.8.6 | Authors contributions.....   | 252        |
| 6.9   | Acknowledgements .....   | 252        |
| 6.10  | Author details .....   | 252        |
| 6.11  | Endnote .....  | 253        |
| 6.12  | Additional files.....  | 253        |
| 6.13  | References .....   | 253        |
|       | <b>Chapter 7: Integration of Findings .....</b>  | <b>267</b> |
| 7.1   | Introduction .....   | 267        |
| 7.2   | Data integration: Mapping findings across the three papers onto NPT constructs .<br>.....  | 268        |
| 7.2.1 | Coherence: How do stakeholders involved in PCTs and wider primary<br>health care context make sense of community participation on PCTs?<br>..... | 269        |
| 7.2.2 | Cognitive Participation: How and why do stakeholders get involved in<br>community participation on PCTs?.....                                    | 271        |

|                   |  |            |
|-------------------|--|------------|
| 7.2.3             | Collective Action: What do stakeholders need to enact community participation on PCTs in daily practice? ..... | 272        |
| 7.2.4             | Reflexive Monitoring: How do stakeholders evaluate the impact of community participation on PCTs?.....         | 276        |
| 7.3               | Key messages from the PhD study .....  | 279        |
| 7.4               | Conclusion .....   | 284        |
| <b>Chapter 8:</b> | <b>Discussion .....</b>  | <b>286</b> |
| 8.1               | Introduction .....   | 286        |
| 8.2               | Summary of Findings.....   | 286        |
| 8.3               | Comparison with Literature .....   | 289        |
| 8.4               | Methodological Critique .....  | 296        |
| 8.4.1             | Limitations .....  | 297        |
| 8.4.2             | Thesis by publication .....  | 298        |
| 8.4.3             | Critical reflection on learning .....  | 299        |
| 8.5               | Conclusion .....   | 300        |
| 8.6               | Recommendations.....   | 301        |
| 8.7               | Directions for Future Research .....   | 302        |
| 8.8               | References .....   | 303        |

|   |            |
|---|------------|
| <b>Appendices</b>   | <b>312</b> |
| Appendix 1: Rationale for Journal Selection and Copyright of Papers.....  | 312        |
| Appendix 2: Examples of deliberative democracy methods which have been applied to primary health care across international settings ..... | 318        |
| Appendix 3a: Ethical approval for each of the three projects .....  | 324        |
| Appendix 3b: Ethical approval for use of photographs in PLA sessions (Paper 2 Chapter 5).....   | 329        |
| Appendix 4: Examples of analytical notes from fieldwork .....   | 331        |
| Appendix 5: Alternative theories considered to be relevant to implementation of community participation on PCTs .....                     | 336        |
| Appendix 6: Triangulation Protocol for Integrated Data Analysis.....  | 338        |
| Appendix 7: Quality and rigour in this PhD.....   | 340        |
| Appendix 8: Survey in Paper 1 .....   | 346        |
| Appendix 9: Topic guide for the focus groups and interviews Paper 3 Chapter 6 .....   | 362        |

## List of tables

|                  |  |     |
|------------------|--|-----|
| <b>Table 1.1</b> | Table outlining three primary care projects, study aims and methods and researcher role on projects and PhD papers .....           | 28  |
| <b>Table 1.2</b> | NPT constructs applied to research questions about community participation on PCTs .....   | 33  |
| <b>Table 2.1</b> | Psychosocial, health status and health service outcomes resulting from community participation as reported in the literature ..... | 48  |
| <b>Table 3.1</b> | Key features of a pragmatic approach to research and how these apply to the current PhD study .....                                | 92  |
| <b>Table 3.2</b> | Participatory health research requirements in the three projects comprising the PhD .....  | 95  |
| <b>Table 3.3</b> | Data sources: Participants and methods employed across the three studies N=629 .....   | 100 |
| <b>Table 3.4</b> | VanWyssberghe and Kahn’s seven common features of a prototypical case study applied to this PhD study .....                        | 102 |
| <b>Table 3.5</b> | Potential pitfalls and mitigating actions when undertaking case study research .....   | 105 |
| <b>Table 3.6</b> | Rationale for using NPT as a good theoretical fit for this PhD .....   | 111 |

|                  |  |     |
|------------------|--|-----|
| <b>Table 3.7</b> | Integration of qualitative and quantitative data at the interpretation and reporting level .....   | 113 |
| <b>Table 4.1</b> | Distribution of occupations in the HSE regions and the survey sample .....   | 133 |
| <b>Table 4.2</b> | Demographics of respondents (n=569) .....  | 135 |
| <b>Table 4.3</b> | Characteristics of primary care teams for named members of formal PCTs (n=388) .....   | 137 |
| <b>Table 4.4</b> | Health professional views of policy implementation; Median rating (1 <sup>st</sup> quartile, 3 <sup>rd</sup> quartile) for all respondents (n=569) and by occupation .....   | 139 |
| <b>Table 4.5</b> | Views on the progress of implementation of primary care teams by members of those teams, Median rating (1 <sup>st</sup> quartile, 3 <sup>rd</sup> quartile) for all named members of formal PCTs (n=388) and by occupation ... | 141 |
| <b>Table 4.6</b> | Rank order of factors required for effective PCT working - views across three largest disciplines .....  | 142 |
| <b>Table 4.7</b> | Ranking of required resources for effective team working by three largest groups .....   | 144 |
| <b>Table 5.1</b> | Case study sites and research participants .....   | 169 |
| <b>Table 5.2</b> | Levers and barriers to community participation on Primary Care Teams (PCTs) using Normalisation Process Theory (NPT) constructs to evaluate implementation; synthesis of findings across research sites .....                  | 179 |
| <b>Table 6.1</b> | PLA techniques employed in Paper 3 Chapter 6 .....   | 217 |
| <b>Table 6.2</b> | Overview of marginalised group participants .....  | 221 |
| <b>Table 6.3</b> | Priorities for action across the participant groups .....  | 242 |

|                  |   |     |
|------------------|---|-----|
| <b>Table 7.1</b> | Levers and barriers to community participation on primary care teams (PCTs) using NPT constructs to evaluate implementation; synthesis of findings across the research papers in this PhD ..... | 281 |
|------------------|---|-----|

### List of Figures

|                   |   |     |
|-------------------|---|-----|
| <b>Figure 3.1</b> | Framework for this research: Adapted from Creswell 2013 - A framework for research the interconnection of worldviews, design and research methods ..... | 97  |
| <b>Figure 3.2</b> | Sequential Exploratory Design approach applied to this PhD underpinned by NPT .....   | 108 |
| <b>Figure 6.1</b> | PLA chart after flexible brainstorming .....  | 218 |
| <b>Figure 6.2</b> | Overview of themes .....  | 222 |
| <b>Figure 7.1</b> | Figure showing intersection of NPT constructs .....   | 285 |

### List of Boxes:

|                |  |     |
|----------------|--|-----|
| <b>Box 1.1</b> | National primary healthcare policy vision for PCTs .....                                       | 21  |
| <b>Box 5.1</b> | Normalisation Process Theory (NPT) theoretical constructs .....                                | 173 |
| <b>Box 5.2</b> | Participatory Learning and Action (PLA) techniques used for data generation and analysis ..... | 175 |
| <b>Box 6.1</b> | Study setting Paper 3 Chapter 6 .....  | 212 |
| <b>Box 6.2</b> | Irish primary care context .....   | 213 |

## Abbreviations

|     |                                   |
|-----|-----------------------------------|
| GP  | General Practitioner              |
| HSE | Health Service Executive          |
| PCP | Primary Care Professional         |
| PCT | Primary Care Team                 |
| PHC | Primary Health Care               |
| PHE | Partnership for Health Equity     |
| PHN | Public Health Nurse               |
| PLA | Participatory Learning and Action |
| PPI | Patient and Public Involvement    |

## List of Publications

Tierney, E., O’Sullivan, M., Hickey, L., Hannigan, A., May, C., Cullen, W., Kennedy, N., Kinneen, L. & MacFarlane, A. (2016) Do primary care professionals agree about progress with implementation of Primary Care Teams: – a cross sectional study. *BMC Family Practice* 17:163. <https://doi.org/10.1186/s12875-016-0541-9>

Tierney, E., McEvoy, R., Hannigan, A. & MacFarlane, A. (2018) Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice. *Health Expectations* –2018;00:1-12. <https://doi.org/10.1111/hex.12692>

O’Donnell, P., Tierney, E., O’Carroll, A., Nurse, D. & MacFarlane, A. (2016) Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study. *International Journal for Equity in Health*, 15:197 <https://doi.org/10.1186/s12939-016-0487-5>

## **Chapter 1: Introduction**

This chapter introduces my PhD thesis *Community Participation in Action: Involving Communities in Primary Care Teams* with reference to the international and national health policy context for the research, the rationale for the study, my role as Researcher and my contribution to the research. The main aim and objectives of the research are outlined, along with the range of stakeholders in the research and the justification for the study design based on three separate primary health care research projects. The theoretical underpinning for the research is introduced and an outline of the thesis chapters is also provided.

### **1.1 International and national policy context for community participation in primary healthcare**

The concept of involving patients and the public in healthcare planning has gained acceptance in recent decades and is enshrined in health policy across a range of international settings [1-12]. Community participation in primary health care as a concept has its origins in the Alma-Ata Declaration of 1978 which stated that *'people have the right and duty to participate individually and collectively in the planning and implementation of their health care'*, [13]p.1 and that effective primary healthcare *'requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care'* [13] p.2. The 'co-production of health' and the fostering of 'equal and reciprocal' interactions are now seen to be core attributes of health service design [14] and have been enshrined in Irish primary healthcare policy since 2001 with the

launch of the National Health Strategy -Primary Care A New Direction Quality and Fairness - A Health System for You (2001) [4] hereafter referred to as the Primary Care Strategy. In this Strategy, Primary Care Teams (PCTs) were identified as a key development to improve primary healthcare (see Box 1.1 for the policy vision for PCTs).

**Box 1.1 National primary healthcare policy vision for PCTs**

The Primary Care strategy 2001 proposed that PCTs would comprise of GPs (private contractors) and HSE employed health professionals including nurses/midwives, health care assistants, home helps, physiotherapists, occupational therapists, social workers and administrative personnel. A wider primary care network of other primary care professionals such as speech and language therapists, community pharmacists, dieticians, community welfare officers, dentists, chiropodists and psychologists would also provide services for the population of each PCT. PCTs were to work with local populations and other agencies, such as community development projects, to identify health and social needs.

PCTs were encouraged to ensure community participation in service planning and delivery. Input from the community and voluntary sector was proposed to enhance the advocacy role of PCTs [4]. Specifically, action 19 of the Primary Care Strategy states that: *‘Community participation in primary care will be strengthened by encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services at local level, primary care teams will be encouraged to ensure user participation in service planning and delivery. A greater input from the community and voluntary sector will enhance the*

*advocacy of primary care teams in ensuring that local and national social environmental health issues, which influence health are identified and addressed'*  
[4]p.39.

The input of patients and communities was also reflected in the subsequent National Strategy for Service User Involvement in the Irish Health Service [15]. Developed by the HSE Office of Consumer Affairs (renamed the National Advocacy Unit in 2010), and in partnership with the Department of Health and Children (DoHC) and other key stakeholders (i.e. union representatives, service users, statutory and voluntary organisations), the Service User Involvement Strategy was produced in the context of several key DoHC and HSE policy and strategy documents, which had previously demonstrated a commitment to service user involvement namely the aforementioned Primary Care Strategy [4], as well as the National Strategy for Mental Health, A Vision for Change [16].

This National Strategy for Service User Involvement uses the term '*service user*' to "*take account of the rich diversity of people in society whether defined by age, colour, race, ethnicity or nationality, religion, disability, gender or sexual orientation, and may have different needs and concerns*" [15] p.6. It uses the term 'involvement' and bases this definition on the WHO definition of community participation to refer to: '*a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in*

*planning, developing and delivering services and in taking action to achieve change'* [17] p.6.

In this strategy, involvement is based on three levels: *'Individual service users: involvement in their own care , Community: involvement in local service delivery and development and National: strategic policy informed through involvement of service user organisations in partnership with health care professionals'* [15]p.5.

More recently, the Health Service Executive reiterated its commitment to service user involvement in “SláinteCare” (2017) [18]. This report, and its accompanying National Service Plan (2018) [19], shows a sustained emphasis on a shift from hospital based to community care, interdisciplinary working and flexible and person-centred services. In the National Service Plan [19], under one of its key reform themes, *Improving Population Health*, it commits to *'secure the engagement of local communities to improve community health and wellbeing,' p.6* and *'seeks to ensure that person centred care that is respectful and responsive to individual needs and values, partners with patients and service users in designing and delivering that care' p.7*. It also commits that a *'key focus will be to listen to the views and opinions of patients and service users and consider them in how services are planned, delivered and improved'* p.20.

This thesis is concerned with community participation and primary health care policy and the explicit reference to community participation on PCTs within that policy. This PhD study is therefore concerned with involvement at the community

level and explores community participation in local service delivery and development as delivered by PCTs. In this thesis the aforementioned WHO definition of community participation is employed [17]. Further discussion of terminology around community participation and debate about related terms and meanings is explored in Chapter 2.

## **1.2 Rationale for this study**

As outlined above, important developments and reform of primary health care in Ireland happened from 2001 with the Primary Care Strategy and specifically the policy imperative to develop PCTs across the country and to ensure community participation on these teams. However, despite this policy context and efforts to implement community participation on PCTs, there are major gaps in our understanding of the purpose, processes and outcomes of community participation [20]. There is limited data across the multiplicity of stakeholder perspectives on implementing community participation in primary care in practice generally, and community perspectives are rarely captured [21]. Furthermore, there is a lack of evidence for how the various stakeholders work together in a primary health care setting to implement community participation within teams. Lack of clarity and agreement between stakeholder groups about the roles of community representatives remains a major obstacle to effective community participation [22-25].

No theoretical underpinning for implementation of community participation in interdisciplinary teams in practice has been published, despite the variety of frameworks and studies about this topic (see Chapter 2) and the call for theoretically

informed, empirical analysis of implementation to generate insights and transferrable lessons for community participation in primary care across settings [26].

These gaps in the literature inspired the topic for this PhD and provided a rationale for this study to investigate the implementation of community participation on PCTs to illuminate the levers and barriers to policy implementation in Ireland.

### **1.3 Researcher Role and Contribution to the Research**

The origin of this PhD is situated within the context of my role as a Senior Researcher at the Graduate Entry Medical School (GEMS) at the University of Limerick. From 2011-2017, I was employed at GEMS as Senior Researcher on three primary care projects which were investigating various aspects of primary health care and implementation of primary health care policy in Ireland.

During this time, it became apparent to me that these projects, though distinct in design and focus, had an important thread running through them which had the potential to tell a narrative about a little understood phenomenon in the primary health care literature - that of implementation of community participation on PCTs. Whilst the three projects were not designed to investigate this explicitly as a phenomenon, there was data inherent in the projects which, if interrogated, could uncover a valuable interpretation about implementing an innovative policy imperative across a variety of primary health care settings. These projects were situated within the context of implementation of primary health care policy in Ireland across the years 2011-2017. Exploiting these rich sources of data to uncover data about a difficult area to research was also supported by a number of factors; using

this data, underpinned and supported by implementation theory, was robust, minimised the risk of research participant fatigue, overcame ethical issues about accessing vulnerable marginalised groups and maximised this opportunity to tell a particular story about levers and barriers to implementation of policy within a variety of primary health care settings that could be transferrable to other primary health care settings nationally and internationally.

An outline of the three projects and their aims, design and methods is presented in Table 1.1 alongside the distinctive aim pertaining to the PhD (see columns 1-4).

The aim of the first project **Towards a Framework for Implementation of Community Participation in Primary Health Care**, was to assess the impact of community participation in primary health care from the perspectives of the key stakeholders involved [27]. Participatory research methods, specifically Participatory Learning and Action (PLA) focus groups and interviews across multiple stakeholders in this project also gathered data about their *perspectives on enactment of community participation via PCTs*.

The second project **Primary Care Reform in Ireland - an Exploration of Interdisciplinary Team Working: Levers and Barriers to Implementation** was conducted to provide a theoretically informed analysis of implementation of interdisciplinary team (Primary Care Team) working in Ireland. In phase 1, an on-line survey was employed to explore what are primary health care professionals' perceptions of progress with PCT implementation and what other bottom-up innovations have developed in their local primary health care settings? This online survey also gathered data about the *perceived importance of community participation*

*on PCTs as a resource for teams and the number of PCTs which had community representatives as a member of these teams.*

The third project **Exploring Levers and Barriers to Accessing Primary Care for Marginalised Groups** was a partnership with a multidisciplinary PCT being established by the Health Service Executive (HSE) and general practitioners (GPs). The overall purpose of the project was to inform the development and functioning of this PCT to support engagement with marginalised patients in its catchment area. Exploratory qualitative focus groups with PLA methods and interviews were employed to *collaborate with marginalised patients and service users to seek their views about accessing primary health care and to better understand their experiences and priorities for action for PCT services.*

Projects 1 and 2 were informed and designed with Normalisation Process Theory (NPT) as an underpinning theory. This theory further supported the theoretical underpinning for this PhD and informed the development of the research questions around community participation on PCTs (see Table 1.2).

The three papers arising from the three projects and addressing the PhD aims comprise chapters 4, 5 and 6 of this thesis and are outlined in columns 5-7 of Table 1.1. Two are qualitative papers using interviews and focus groups, employing PLA research methods to include key stakeholder groups in the exploration of a multi-perspectival exploration of community participation on PCTs in Ireland. The third paper is a quantitative survey exploring health care professional attitudes towards community participation on PCTs and implementation of primary health care policy in Ireland.

**Table 1.1: Table outlining three primary care projects, study aims and methods and researcher role on projects and PhD papers**

| <b>Wider project title</b>   | <b>Aim of wider project</b>  | <b>Time frame of project</b> | <b>Aim pertaining to PhD study</b>  | <b>Methods</b>   | <b>Published paper</b>  | <b>Contribution to the project and published paper</b>  |
|--|--|------------------------------|---|--|---|---|
| <b>Project 1:<br/>Towards a Framework for Implementation of Community Participation in Primary Health Care</b> | To assess the impact of community participation in primary health care from the perspectives of the key stakeholders involved. | 2011-2014                    | To conduct a theoretically informed, multi-perspectival empirical analysis of the implementation of community participation via Primary Care Teams (PCTs) in Ireland. | <p>A case study analysis of national on-going community involvement projects designed to enable disadvantaged communities to participate in PCTs.</p> <p>Qualitative research methods using interviews and Participatory Learning and Action (PLA) focus groups across key stakeholder groups.</p> | <p><b>Paper 2: March 2018</b></p> <p><b>Reference</b></p> <p><u>Tierney, E., McEvoy, R., Hannigan, A. &amp; MacFarlane, A. (2018) Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice. <i>Health Expectations</i> – 2018;00:1-12. <a href="https://doi.org/10.1111/hex.12692">https://doi.org/10.1111/hex.12692</a></u></p> | <p>Design of study fieldwork, led all fieldwork focus groups and interviews, led on data analysis and write up.</p> <p>Paper conception and design (with supervisors AMacF, AH).</p> <p>Review of literature – lead.</p> <p>Drafting of manuscript – first author and lead with contribution from co-authors (AMacF, RME and AH).</p> <p>Critical revisions of manuscript (with supervisor AMacF and AH).</p> <p>Led on final preparation and editing of manuscript</p> |

| Wider project title  | Aim of wider project   | Time frame of project | Aim pertaining to PhD study  | Methods  | Published paper   | Contribution to the project and published paper   |
|--|--|-----------------------|--|--|---|---|
|  |  |                       |  |  |   | and submission to journal.  |
| <b>Project 2:<br/>Primary Care Reform in Ireland -<br/>An Exploration of Interdisciplinary Team Working: Levers and Barriers to Implementation</b> | To conduct a theoretically informed analysis of implementation of interdisciplinary team working in Ireland. | 2014-2017             | To better understand the perspectives on policy implementation of participating professional groups and to understand their views about community participation on PCTs. | Quantitative study using an online survey with GPs and Health Service Executive (HSE) Primary Health Care (PHC) professionals. | <b>Paper 1: July 2015</b><br><b>Reference;</b><br><u>Tierney, E., O’Sullivan, M, Hickey, L, Hannigan, A, May, C, Cullen, W, Kennedy, N, Kinneen, L &amp; MacFarlane, A.(2016) Do primary care professionals agree about progress with implementation of Primary Care Teams: – a cross sectional study. <i>BMC Family Practice 17.1 (2016): 163.</i> <a href="https://doi.org/10.1186/s12875-016-0541-9">https://doi.org/10.1186/s12875-016-0541-9</a></u> | Design of survey instrument with input from wider team members.<br><br>Distribution of survey via email and follow up. Led communications pertaining to national survey.<br><br>Contribution to statistical analysis –led by AH.<br><br>Paper conception and design (with supervisors AMacF, AH)<br>Review of literature – lead.<br>Drafting of manuscript – first author and lead with contribution from co-authors.<br>Critical revisions of manuscript (with |

| Wider project title   | Aim of wider project   | Time frame of project | Aim pertaining to PhD study   | Methods  | Published paper  | Contribution to the project and published paper   |
|---|--|-----------------------|---|--|--|---|
|   |  |                       |   |  |  | supervisor AMacF and AH).<br><br>Led on final preparation and editing of manuscript and submission to journal.  |
| <b>Project 3:<br/>Exploring Levers and Barriers to Accessing Primary Care for Marginalised Groups</b> | To inform the development and functioning of a PCT to support engagement with marginalised patients in a deprived inner city area. | 2014-2015             | To involve members of marginalised groups in the development of a local PCT by incorporating their views about priority areas for action. | Exploratory qualitative research design using interviews and PLA focus groups with marginalised groups availing of PCT services. | <b>Paper 3: December 2016</b><br><br><b>Reference:</b><br>O'Donnell, P, Tierney, E, O'Carroll, A. Nurse, D. & MacFarlane, A. (2016) Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study. <i>International Journal for Equity in Health</i> , 15:197<br><a href="https://doi.org/10.1186/s12939-016-0487-5">https://doi.org/10.1186/s12939-016-0487-5</a> | Design of study fieldwork, led all focus groups.<br><br>Co- led on data analysis and write up.<br><br>Paper conception and design (with supervisor AMacF & co-author POD).<br><br>Review of literature – co-lead.<br>Data analysis lead (with input from co-authors).<br><br>Drafting of manuscript 2 <sup>nd</sup> author.<br>Critical revisions of manuscript (with POD and AMacF). |

| Wider project title | Aim of wider project | Time frame of project | Aim pertaining to PhD study | Methods | Published paper | Contribution to the project and published paper    |
|---------------------|----------------------|-----------------------|-----------------------------|---------|-----------------|--|
|                     |                      |                       |                             |         |                 | Joint final preparation and editing of manuscript. |

#### **1.4 Research Aims and Objectives**

The aim of this study was to conduct a multi-perspectival theoretically informed, empirical analysis of the implementation of community participation on Primary Care Teams (PCTs) in Ireland.

The objectives were to:

- Compare perspectives across stakeholders involved in implementing community participation on PCTs
- Identify levers and barriers to implementation of community participation on PCTs
- Generate recommendations to support implementation of community participation on PCTs as a policy innovation

#### **1.5 Participants/Stakeholders**

There were five stakeholder groups in this study which informed the multi-perspectival analysis;

- (i) Community representatives<sup>2</sup>
- (ii) Health Service Executive (HSE) health professionals and practitioners who are working on the PCTs and in the wider primary care environment

---

<sup>2</sup> Community representatives in this context were defined as: “individuals, who are ‘representing’, representative, and/or ‘consultative’ of one or more populations or affinity groups. They can be stakeholders, opinion leaders, organisers and advocates. They serve as a platform and channel for information and voices of community, communicating ideas and concepts between community and health and social services and who hold people and processes accountable [28] p. 4.

- (iii) HSE service planners and policy makers who oversee the development of PCTs and implementation of primary care policy
- (iv) GPs working with PCTs
- (v) Patients/ members of marginalised groups interacting with or receiving services from PCTs

### 1.6 Theory underpinning this PhD

Normalisation Process Theory (NPT) was the theory which underpinned this study and allowed me to extract and explore data pertaining to the implementation and practice of community participation on PCTs across three primary health care projects, multiple primary health care settings and the range of stakeholders involved with PCTs in Ireland. I applied the four NPT constructs (Table 1.2) as a heuristic device to explore the research questions to address the aim and objectives of the study. Further discussion of the application of NPT as an underpinning theory across this study is discussed in Chapters 3, 4, 5 and 7.

**Table 1.2: NPT constructs applied to research questions about community participation on PCTs**

| <b>NPT construct</b>    | <b>Research question pertaining to community participation on primary care teams (PCTs)</b>                               |
|-------------------------|---|
| Coherence               | How do stakeholders involved in PCTs and wider primary health care context make sense of community participation on PCTs? |
| Cognitive participation | How and why do stakeholders get involved in community participation on PCTs?  |
| Collective action       | What do stakeholders need to enact community participation on PCTs in daily practice?                                     |

|                      |   |
|----------------------|---|
| Reflexive monitoring | How do stakeholders evaluate the impact of community participation on PCTs? |
|----------------------|---|

## 1.7 Thesis Outline

This thesis is presented as an article based PhD.

Chapter 1, the Introduction provides a brief overview of international and national policy context for community participation in primary health care, an outline of the three projects which informed this work, and the three peer-reviewed papers included in this thesis. The research aims and objectives of the PhD as well as an introduction to NPT, the theory which underpins this thesis, are outlined.

Chapter 2 the Literature Review provides an overview of the relevant literature in this research area.

Chapter 3 outlines the methodology of the PhD.

Chapters 4, 5 and 6 are the published papers as outlined in Table 1.1 (column 6). All of these papers are published in international peer-reviewed journals. (See Appendix 1 for rationale for journal selection and copyright of papers).

Chapter 7 is an integrated analysis of findings across the three published papers which are mapped onto the constructs of NPT.

Chapter 8 is a discussion of findings in the context of the PhD questions and the Irish and international policy context.

Chapters 3 and 7 are in addition to the suggested structure for article based PhD in the UL Handbook of Academic Regulations and Procedures. Chapter 3 offers more detail on key methodological issues than can be provided in the academic papers.

Chapter 7 provides an integrated analysis beyond the analysis in the published papers which is key for answering the PhD questions.

Appendices are included at the end of the thesis.

Some formatting changes have been made to aid presentation and readability of the thesis. For example, figures, tables and references reported in Chapters 4, 5, 6 are presented according to the requirement of the published papers. Relevant bibliographies are provided within each chapter to improve clarity.

## **1.8 Summary**

This study was motivated by my work as Senior Researcher on three separate primary health care projects at the University of Limerick between 2011 and 2017. During this time, I recognised an opportunity to interrogate data inherent in the three projects about a little understood phenomenon in Irish primary health care policy - that of community participation on PCTs. This thesis tells the story of the implementation of community participation on PCTs across the three projects and multiple settings and stakeholder perspectives using a variety of data collection methods. The data uncovered, offers an insight into the practice of community participation on PCTs in Ireland using NPT as a theoretical underpinning to support findings. It is presented as an article based PhD with supporting additional chapters.

## 1.9 References

1. Charles, C., & DeMaio, S., *Lay participation in health care decision-making: a conceptual framework*. Journal of Health Politics, Policy and Law 1993. **18**(4): p. 881-904.
2. Health Council of Canada, *Teams in Action Primary Health Care Teams for Canadians*. 2009, Health Council of Canada: Toronto
3. Department of Health, *Involving patients and the public in healthcare: response to the listening exercise*, Department of Health, Editor. 2001, UK Department of Health: London.
4. Department of Health and Children, *Primary Care: A New Direction*. 2001, Department of Health and Children: Dublin.
5. WHO, *Primary Health Care: Now More Than Ever*. 2008, WHO Geneva.
6. Neuwelt P.M., *Community participation in primary care: what does it mean 'in practice'?* Journal of Primary Health Care, 2012. **4**(1): p. 30-8.
7. Welsh Government, *Parliamentary Review of Health and Social Care in Wales Interim Report*. 2017, Welsh Government.
8. Welsh Government, *Our plan for a primary care service for Wales up to March 2018* 2014, Welsh Government.
9. Scottish Health Council, *Promoting, supporting and developing public involvement in primary care* 2013, The Scottish Health Council.
10. Draper, A.K., G. Hewitt, and S. Rifkin, *Chasing the dragon: developing indicators for the assessment of community participation in health programmes*. Social Science & Medicine, 2010. **71**(6): p. 1102-1109.
11. Morgan, L.M., *Community participation in health: perpetual allure, persistent challenge*. Health Policy and Planning, 2001. **16**(3): p. 221-230.

12. Sarrami-Foroushani, P., et al., *Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review*. BMC Health Services Research, 2014. **14**(1): p. 402.
13. WHO, *Poverty and social exclusion in the WHO European Region: health systems respond*. 2010, WHO Regional Office for Europe: Copenhagen.
14. WHO, *WHO global strategy on people-centred and integrated health services: interim report*. 2015.
15. Department of Health and Children, *Strategy for Service User Involvement in the Irish Health Service 2008-2013*. 2008, Health Services Executive and Department of Health and Children: Dublin.
16. Government of Ireland, *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Department of Health and Children, Editor. 2006, Government of Ireland Dublin.
17. WHO, *Community participation in local health and sustainable development: approaches and techniques*. 2002, WHO: Geneva.
18. Government of Ireland, *Committee on the Future of Healthcare Sláintecare Report*. 2017, Houses of the Oireachtas: Dublin
19. Health Service Executive, *National Service Plan 2018*. 2018, Health Service Executive: Dublin.
20. Kenny, A., et al., *Community participation for rural health: a review of challenges*. Health Expect, 2015. **18**(6): p. 1906-1917.
21. Preston, R., et al., *Community participation in rural primary health care: intervention or approach?* Aust J Prim, 2010. **16**(1): p. 4-16.

22. Nathan, S., L. Johnston, and J. Braithwaite, *The role of community representatives on health service committees: staff expectations vs. reality*. Health Expect, 2011. **14**(3): p. 272-284.
23. Fudge, N., C.D. Wolfe, and C. McKeivitt, *Assessing the promise of user involvement in health service development: ethnographic study*. BMJ, 2008. **336**(7639): p. 313-317.
24. Hogg, C. and C. Williamson, *Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees*. Health Expect, 2001. **4**(1): p. 2-9.
25. Hogg, C.N., *Patient and public involvement: what next for the NHS?* Health Expect, 2007. **10**(2): p. 129-138.
26. McEvoy, R. and A. MacFarlane, *Community participation in primary care in Ireland: the need for implementation research*. Primary Health Care Res, 2013. **14**(02): p. 126-139.
27. MacFarlane, A., Tierney, E. McEvoy, R., *A Framework for Implementation of Community Participation in Primary Health Care*. 2014, Univeristy of Limerick and Health Service Executive: Limerick.
28. Health Service Executive, *Service User Involvement and Primary Care Framework Document*, H.S.E.-R.S.I. Group, Editor. 2011: Dublin

## **Chapter 2: Community Participation in Primary Health Care - the Literature**

### **2.1 Introduction**

This chapter gives an overview of the literature pertaining to community participation. The review of the literature for this chapter built on a previous published review of service user involvement in primary care research and health service development, based on a critical interpretative synthesis approach published in 2016 [1] . For this review, a multidisciplinary interagency team with community representation conducted a search of English language peer reviewed papers published from 2007-2011. We sought a purposeful sample of papers integrating quantitative and qualitative data. Databases searched across EBSCO host included Academic search complete, Ageline, CINAHL plus with full text, Health Source (Nursing/Academic edition) Medicine, Psychology and Behavioural Sciences Collection, SocINDEX with full text.

This iterative reflexive approach to searching, sampling, appraising and analysing the literature continued to include publications up until 2019 at the time the thesis was submitted. This process included setting up alerts in various databases described above, Google Scholar and hand searching and chain-referencing papers discovered in the process.

In the preparation of this chapter, additional literature areas were searched which included studies pertaining to deliberative democracy methods, with a specific emphasis on health care delivery in western democracies. The literature on implementation theories with a specific focus on Normalisation Process Theory and its application to primary health care settings was also included.

This Chapter is divided into three sections. The first section outlines the myriad of definitions and conceptualisations of community participation in the literature, the frameworks to describe community participation in primary health care and the reported outcomes of community participation initiatives. The second section outlines the operationalisation of community participation in practice in primary health care structures and some of the challenges with these. It also describes the conditions required to implement community participation in primary health care structures. The final section outlines the value of implementation theory as a means to explore levers and barriers to implementation of community participation in practice.

## **2.2 Concepts of community participation in primary health care: frameworks and appraisal of outcomes**

As outlined in Chapter 1, the concept of community participation in health service provision has been around since the World Health Organisation published the Alma-Ata Declaration in 1978 [2] and is now enshrined in international health policies [3-15].

*WHO defined primary health care as: "Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community by means acceptable to them at a cost that the community and the country can afford to maintain at every stage of their development in a spirit of self-reliance and self-determination.... It is the first level of contact of individuals, the family and the community with the national health system, bringing health care as close as possible*

*to where people live and work and constitutes the first element of continuing health care process"*[2]p1. This people-centered approach to care is available, accessible and affordable for all; it considers the relevance and quality aspects of care, such as the responsiveness adequacy and continuity of healthcare and it empowers individuals and communities through active involvement and participation [16].

Primary health care starts from the *exploration of the expectations of the patient and focuses on the empowering of the individual health and strength (health promotion), addresses individual and cultural norms and values, and takes, when needed the advocacy role* [17]p.17. A primary health care team acts as the hub in the navigation of the patient in the health care system. Primary health care teams do not only address the needs of the individuals, but are also looking at the community, especially when addressing social determinants of health [17].

This inter-disciplinary team approach helps to develop the capacity of services at primary care level and the increased provision of community and home based supports should enable patients to stay at home with support and prevent crisis hospital admissions [6][18, 19].

Furthermore, there are clear indications that primary care reduces social inequalities in health through empowerment of individuals and communities and social cohesion [17].

Since the 1970s there has been increased interest in participation in health and the developments which led to this has included; the emergence of the disabled peoples' and other service users 'movements; the re-emergence of interest in ideas of 'human need', with a particular concern with social participation; the rekindling of interest in the idea of citizenship, particularly linked with concerns about 'social exclusion; and

finally, postmodernism, where the highlighting of diversity has also encouraged concerns with the equal rights, inclusion and participation of different groups and identities [20].

However, despite the international policy context and efforts to implement community participation in primary health care, there are major gaps in our understanding of its purpose, processes and outcomes [21]. There is a large amount of literature on community participation that crosses both subject and disciplinary boundaries and there is a profusion of definitions [14] and *terms* related to the concept of community participation; for example, community involvement, community development, community empowerment, community capacity, community engagement and community competence (see [22-25]). A standard definition remains both elusive and contentious [14] and this continues to plague the field.

### **2.2.1 Conceptualisation of community participation**

Taken *separately*, the words ‘community’ and ‘participation’ are debated terms [21].

The term ‘*community*’ is used loosely and ambiguously in the literature [26]. For example, common definitions of ‘community’ include people in a relatively bounded geographical area, a social space with interactions and transactions, people with social and cultural affiliations and common norms and customs, and people who drive locally beneficial solutions [27, 28]. There is a premise of a somewhat cohesive group of individuals with a common purpose and shared focus [21]. One component of community which is important to health professionals is that of target populations or ‘at risk’ groups rooted in the epidemiological view of community.

These groups of people need to be identified so that resources can be allocated to the greatest effect [29].

The term '*participation*' also has a wide range of definitions and meanings in the literature [21, 23, 30] and defies any single attempt at definition or interpretation [31]. The WHO defines participation as 'collaboration' in which people voluntarily, or as a result of some persuasion or incentive, agree to collaborate with an externally determined project often by contributing their labour and other resources in return for some expected benefits [31]. It is also seen as an *empowerment tool through which local communities take responsibility for diagnosing and working to solve their own health and development problems* [12] p. 221. Terms are used interchangeably in the literature and refer to '*participation*' '*involvement*', '*consultation*' '*engagement*' and '*empowerment*' [12, 25, 31-34]. Participation has been described as an umbrella term, suggesting an on-going, active relationship with shared power and ownership, understood in different ways by different people [21], creating confusion over what participation is for, and how to do it [35] thus *becoming mired in a morass of competing referents* [36]p. 269.

Taken *together* then, the term '*community participation*' has been described variously by different authors [35, 37-41] as a social process and an ideal discussed on a continuum between community readiness and community empowerment [38], brought about through social interactions expressed collectively, embedded in a community of place [42], and directed to the achievement of a specific task perceived to lead to community betterment [39]. Community participation takes

place in a specific organisational and social context from which it cannot be divorced [42]. In this context, it is *instrumental*; a means to an end [35, 42]. The end is having cost-effective, relevant and accessible health services [42]. It is also a *process*; focused on sustained active involvement of communities in service development [42]. Something about the shared interests of a group is relevant to the proposed activity; for example, a community of people living with a particular condition or need for a service [35].

The *delineation* of the two terms means that there is a tendency to see a community as a target group for a health intervention, and participation as the response of the group to take up advice and activities that have been proven to deliver better health [43]. However, according to Taylor et al, there is no separation between ‘community’ and ‘participation’[26]. One definition put forward is the WHO definition, ‘*a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change*’ [32] p.6.

### **2.2.2 Frameworks describing community participation in primary health care**

The community participation literature has produced numerous typologies or frameworks to guide practice and evaluation of community participation strategies in the health sector. These frameworks are useful starting points for differentiating the approaches for involving people in planning and decision-making for health services [44]. Most have been developed based on a continuum of power-sharing, the most

famous being Arnstein's ladder of participation [45]. This seminal work from 1969 has been extremely influential for other typologies. Arnstein ranks the different degrees of citizen participation starting at the lowest rung of manipulation and ascending upwards to the highest level of participation, citizen control, where power is directly transferred from government to people [14]. Critics of Arnstein have identified issues with the ladder, including lack of consideration given to the quality of the participation and limitations associated with the categories chosen [21]. Some say that it fails to acknowledge that, for different people and different purposes, different levels may reflect successful participation [46]. Tritter and McCallum [47] refer to 'dangerous snakes' in Arnstein's ladder and conclude that the ladder analogy does not recognise that participation itself can be a goal for some users. They propose that community participation is more like a 'vague mosaic' than a ladder with defined rungs [47]. They propose that different methods are required to secure active user participation in health service decision-making at individual, collective, and organisational levels. Rifkin and colleagues [29] developed a tool to assist those involved in primary health care programmes to describe participation in their programme and upon that basis plan their future actions [29]. Their model can be utilised as an evaluation framework that enables an analysis of the process of participation and links this with health and programme outcomes. The continuum of participation and framework is based upon a spidergram and it can be used prospectively by those involved in programme design and implementation to further understanding of community participation and its relationship with health outcomes, as well as key programme outcomes, such as sustainability [29]. Similarly, Andy Gibson and colleagues developed a framework to encompass the cultural, political and social dynamics of participation. They identified four dimensions to map the

terrain of interactions between different kinds of expertise, in which they claim new knowledge spaces may be constructed. They view these dimensions as points along a continuum that may move to and fro over time and are interdependent [48]. This framework offers either a medium for reflection on current practice or a means to develop new ways of thinking about participation. *Preston and colleagues* [37] developed a typology to define, illustrate and clarify the different conceptual approaches to community participation. Four conceptual approaches to community participation were put forward: contributions, instrumental, community empowerment and developmental. These approaches and their associated methods involve planning for, creating access to and providing all types of community-based health services and programmes including health promotion, health planning, priority setting, evaluation and community capacity building [37]. However, the various conceptual approaches to community participation in this particular typology often overlap and are difficult to distinguish in practice.

On the other hand, Popay's (2006) conceptual model on the 'pathways from community engagement to health improvement' [49] used a framework to categorize types of community participation and its outcomes. Popay's model suggests that community participation occurs on a continuum, ranging from basic information provision through to community control. Similar to Arnstein's ladder of participation, the model is read from the bottom up, with increasing degrees of community participation, empowerment and control along a continuum ranging from 'informing', 'consultation', 'coproduction', 'delegated power' and 'community control'. However, differing from Arnstein, these pathways are connected with health outcomes so that impact can be measured. According to Popay, the lower levels of community engagement; i.e. 'informing' and 'consultation' do not have an

impact on intermediate social outcomes, hence only lead to relatively small improvements in health and service outcomes. As the degree of community participation, empowerment and control increases, so does the impact on outcomes.

Scholars have critiqued these participation frameworks for being too generic and ignoring contextual and situational aspects of community participation [14, 36, 47, 50] and have argued that the search for a “gold standard” framework for community participation that can be replicated across different contexts is neither realistic nor appropriate. Furthermore, the lack of conceptual clarity of the core elements that make up a framework [14, 36], and limited rigorous evaluation of the frameworks in different practice settings pose challenges to the successful use and implementation of evidence-based practice frameworks [44]. There has been limited use of theory, to study community participation in practice [35, 51, 52]. Using theory to understand communities, and to explore the ways in which the community participates, makes explicit the structural, cultural, and institutional factors that support or impede community participation [26].

### **2.2.3 Appraising community participation in primary health care: evidence of impact of community participation on primary health care**

There have been numerous reviews which have attempted to appraise the outcomes of community participation on health for service users, community members, or health services e.g., [30, 34, 41, 53-55]. These outcomes can be broadly categorised

as, psycho-social outcomes, health status outcomes and health service outcomes (see Table 2.1). Benefits range from development of personal skills, empowerment and reduced isolation to improved health outcomes, awareness of health services and improvement in service access as well as development of new services and more informed policy initiatives. Unintended negative consequences have also been reported. The impacts on health professionals engaged in community participation initiatives was beyond the scope of this review.

**Table 2.1: Psychosocial, health status and health service outcomes resulting from community participation as reported in the literature**

| Category of outcome           | Reported outcome and source of evidence  |
|-------------------------------|--|
| <b>Psycho-social outcomes</b> | Builds capacity in terms of developing new skills and knowledge and confidence to engage in new activities [41, 54]<br>Equips communities for regeneration activities [54]<br>Increases political efficacy [54]<br>Heightens sense of responsibility and /or control over resources [21, 35, 40, 41]<br>Builds new and strengthened relationships, reduces isolation, empowerment, improved social support, being listened to by professionals [13, 21, 40, 54-56]<br>Increases self-confidence, self-esteem, sense of personal empowerment and social relationships [34]<br>Can have unintended negative consequences including exhaustion and stress, consultation fatigue and disappointment [34]<br>The physical demands of participation are onerous for individuals with disabilities [34] |
| <b>Health status outcomes</b> | Reduction in neonatal, stillbirth and new-born mortality rates [37]<br>Increased utilization of antenatal and perinatal care [37]<br>Improved cancer awareness, mental well-being, increased rates of breast feeding, decrease in rates of post-natal  |

|                                |   |
|--------------------------------|---|
|                                | depression, decreased number of childhood accidents, fewer cases of asthma [56]<br>Perceived health benefits e.g., improved physical fitness, healthier nutrition and reduced alcohol and cigarette consumption [34, 37]  |
| <b>Health Service Outcomes</b> | Positive impacts on health service improvement [26, 37, 57, 58]<br><br>Makes policy initiatives more sustainable [59]<br><br>Improves service access, utilisation, quality and responsiveness [30, 37, 55, 56, 60]<br>Leads to design of culturally appropriate interventions [37]<br>Leads to development of new services (such as advocacy, employment initiatives, and crisis services) [60, 61]<br><br>Benefits for social capital (strengthening relationships and trust), for bridging social capital (making links across sectors) and benefits for partnership working [54, 55] |

Despite the number of studies reviewing the evidence for community participation in primary health care, there are few rigorous studies that have *definitively* measured the effects of community participation in terms of health outcomes, wellbeing and quality of life [37, 51, 57, 62]. According to Zakus and Lysack reputed benefits of community participation are just that – reputed [40]. A number of difficulties contribute to this, for example; multiple reasons for undertaking participation are often bundled together leading to confusion about the relationships between different outcome areas [35], the aforementioned diversity in definitions of community participation used, methodological variations across studies [54] and poor methodological quality [26, 40, 55]. The picture is further complicated by the specific cultural, historical, social, economic and political environments in which the studies take place [29]. Disentangling the effects of local participation from other affects is also complicated [40, 55]. Furthermore, it is more usual to capture the health outcomes than to analyse the messy processes themselves [42].

Given the challenges with conceptualisation and appraisal, it is important that individual projects and research studies are clear about the specific kind of community participation being researched and the context in which the initiatives or projects take place. The focus of this thesis is on community participation as a process (as outlined in Chapter 1) and the involvement of communities in statutory primary health care services in western democracies. The plethora of literature from the global south and the rich tradition of community participation in these regions is recognised and acknowledged (see [43, 63]) . However, the scope of the literature review for this study was limited to western democracies to give due regard to the political context in which primary health care is delivered and the focus of community participation programmes in these countries which is different from those in the global south. Furthermore, given the interest in this thesis is on Ireland's primary care policy implementation, this chapter focuses on inclusion of literature from western countries only.

The next section describes what is known about the operationalisation of community participation in these contexts.

### **2.3 Operationalisation of community participation in western democracies**

Deliberation refers to a discussion that involves the careful and serious weighing of reasons for and against some proposition, or to an interior process by which an individual weighs reasons for and against courses of action [64]. Central to this is the notion of collective “problem-solving” [64-67]. Meaningful deliberation is enhanced if participation is diverse, inclusive, and descriptively representative and if

participants understand that their deliberations will influence policy development [68, 69]. Deliberative democracy processes are a recent phenomenon in the health sector and have been incorporated into a broad grouping of methods to enact community participation in primary health care. These have been linked to health policy imperatives which have espoused the input of communities into primary health care delivery processes [30, 70-76].

### **2.3.1 Collective participation and deliberative democracy methods**

This section outlines examples of deliberative methodologies which are employed to enact collective participation in primary health care in various developed countries.

A table also summarises these methodologies in Appendix 2.

#### **Ireland:**

As outlined in Chapter 1, the policy vision in Ireland is that at local level PCTs are encouraged to ensure participation in service planning and delivery. A greater input from the community and voluntary sector was proposed to enhance the advocacy role of PCTs [6]. Consumers will have a greater input into needs assessment and a greater input from the community and voluntary sector to enhance that advocacy role of PCTs in ensuring that local, national, social and environmental issues which influence health are addressed. This includes community representatives at PCT meetings and input via community health fora [6].

## **United Kingdom England, Scotland and Wales:**

Community Participation in primary health care has been embedded in health policy in the UK since the 1990s [5, 9-11, 77-79]. Similar to Ireland, policy aims to increase awareness and support and promote public engagement activities within primary health care and improve links between primary health care and local communities. Methods to enact community participation have included: Citizens Jury [30, 73], lay representatives on Primary Care Trusts [80], Patient Participation Groups (PPGs) [74, 75, 81, 82], Critical Friends Groups (CFGs) [83] and Clinical Commissioning Groups (CCGs)[84]. The **citizens' jury** is one of the most common deliberative methods used in the British health system [73, 85]. It is used by UK health authorities as a method for incorporating community values into local decision-making processes [86]. PPGs, CFGs and CCGs are most similar to the Irish approach of having community representatives on PCTs. They developed as methods for substantive participation in general practice across England, Scotland and Wales, [9, 10, 81, 83, 87]. The main activity of these groups is giving advice and feedback on services provided by the practice, but a lack of nationally agreed roles means the remit of groups varies widely [82, 87]. Roles include providing the patient perspective on service provision and health matters such as improving communication between the practice and its patients, influencing the development of services, liaising with other organisations both statutory and voluntary, contributing to the gathering of patient views including supporting and publicising patient surveys, and encouraging research [75]. The process is a combination of patient participation and quality improvement [83].

## **Australia:**

Similar to the UK, in Australia, community participation in primary health care is embedded in policy since the 1990s [88]. Methods to enact community participation in health care take many different forms including: Medicare locals [89], Citizen juries [30] and Community Representatives on Health Service Committees [88] (see also [90]).

Most similar to the model in Ireland and the UK are **Medicare locals** or **Community representatives on health service committees**. As the primary health care partners of Local Hospital Networks, **Medicare locals** support and enable better integrated and responsive local primary health care services. Their remit goes beyond the primary care or GP practice, similar to the Irish model. As independent bodies, they work across boundaries in primary health care and create interfaces with the acute and aged care sectors. Similar to the Irish community representatives' roles, Medicare Locals also have responsibility for population health planning and needs assessment for their regions, identifying gaps in primary health care services, and developing and implementing strategies, in collaboration with communities, population groups and service providers that address these service gaps. Similar to Medicare locals, but specific to Area Health Services, the roles of **community representatives on health service committees** are to protect the interests of carers, consumers and the community. Representatives are chosen to reflect as much as possible the diversity of the local community. Many are active users of health services, carers or people with an experience or understanding of mental illness or a disability.

Also similar to the UK, **Citizens' Juries** have also been employed in Australia where community representatives discuss and reflect on questions of interest against a backdrop of resource restraints [30]. They bring together members of the public (jurors), and provide structured fora for discussion of relevant information provided by 'expert witnesses'. They are an attempt to bridge the gap between 'top down' consultations that entail little involvement, and 'bottom up' community participation based entirely on lay knowledge and interests [73].

### **New Zealand:**

Community Participation in Primary Health Care Organisations has been embedded in New Zealand's Primary Health Care Strategy [91] and in Primary Health Organisations (PHOs) since 2002 [8]. PHOs must demonstrate that their communities, iwi (traditional Māori family groups or descendants), and consumers are involved in their governing processes and that the PHO is responsive to its community. The District Health Board (DHB) must be satisfied that community participation in PHO governance is genuine and gives the communities a meaningful voice [92]. Different types of PHO lead to different expressions of community engagement. As each PHO has a unique history of local relationships, there is no 'gold standard' for engaging communities in PHOs [60].

**Canada:**

Community Participation in primary health care has been embedded in Canadian health policy since 2009 [4]. There have been a number of methods employed to do this: community needs analysis [4], consultations with community [4] and dialogue sessions [93]. Similar to the role of Medicare locals in Australia or community representatives on PCTs in Ireland, community needs analysis and community consultations are used as methods to respond to the needs of the community, including the allocation of resources for chronic health conditions e.g., [4]. More similar to the citizen jury model, dialogue sessions engage representative groups of ordinary “unorganised” citizens who work through complex issues and make value based choices [93]. These dialogues engage members of the public on important issues before decisions are made.

**The Netherlands:**

No health care policy was located in the literature which explicitly embeds community participation in primary health care in the Netherlands. However, two papers of interest in this area were sourced which identified two methods for participation in primary health care in the Netherlands.

Similar to Ireland and the UK, patients may give their opinion about primary health care facilities and may also be involved in setting priorities or discussing self-management in care provision (e.g., diabetes) or may participate in the organisation of preventative activities together with the primary care facility. Community members may also be consulted for improving health care programmes for the

chronically ill or for providing advice in the organisation or policy making of primary care practices as a whole [94].

A different model from those already described is the Neo Corporatist Model [95].

**Patient representatives** via patients' organizations are asked to represent the interests of patients in formal health-care decision making [95]. All patient organizations may participate in decision-making processes. Patient organizations are recognized by the state and are called the third sector. There are hundreds of disease specific patient organisations. Individual patients can become members of these organisations. These organisations are members of larger umbrella organisations who work together in regional and national umbrella organisations. Most of the work of patient organisations is carried out by volunteers and the professionals support the work of umbrella organisations. Interest groups then depend on the opportunities the system gives them to influence decision making. The organisations are seen as legitimate stakeholders and are asked to participate in many decision-making processes as fitting with neo-corporatist or *poldermodel*. There is no formal selection of organisations that can participate, all can partake if they wish to. The position of the patient organisations is legitimised by the contribution of their experiential knowledge.

### **Italy:**

The *Servizio Sanitario Nazionale* (SSN – National Health Service) was created in 1978. The reform of 1978 introduced, for the first time, universal health care and developed a decentralisation process based on regional and local authorities. The reform recognised citizens' participation as a guiding principle and a strategic point

in the whole process of reorganising the health system. The mechanism to enact community participation in primary health care at regional level in Italy is Mixed Advisory Committees (MACs) [85]. MACs operate in both health districts and hospitals with the objective of monitoring and assessing the quality of health care from the users' perspective [85]. MACs are composed of representatives of patients and users' associations and of other advocacy groups, of managers and health professionals.

## **Belgium**

The Belgian health care system is fundamentally based on the 1963 Health Insurance and Hospital Acts [96]. The management of primary care in Belgium is mostly at the federal level, but a culture of discussion and interaction between the different stakeholders exists at the community level, although they are not involved in the final decisions. Inspection of health care is organized at the community level. The communities are responsible for primary care structures for mother and child care and health at school. At the federal level, no recent health policy acts show a clear vision on current and future primary care provision [96].

In Belgium, strategies such as Community Oriented Primary Care (COPC) involve the local community in a continuous process of information gathering, including the design of health-need assessments, planning, and intervention and monitoring of local outcomes [97].

COPC [98] is a model that uses topics from the individual provider–patient encounter as a starting point. The COPC cycle starts with defining the community (e.g., the neighborhood, a patient list). Physicians work together with the community to understand health problems and to establish priorities for finding

solutions to these problems. It combines individual patient and physician practice data with public health data at the community level, leading to a “community diagnosis.” The community diagnosis describes the “health status of the community as a whole or of defined segments of it.” To develop an intervention, physicians consult other data, but they also involve the community. This can be achieved either by directly consulting participants in the COPC community or indirectly by consulting local health workers. Community participation in all phases of the process is mandatory and is vitally important to ensure and enhance the accuracy and acceptability of the intervention [99, 100].

### **2.3.2 Critique of methods to enact community participation in primary health care**

The methods outlined above promote people’s involvement and encourage them to contribute to and take some responsibility for the provision of services to promote health. These methods imply a partnership among individuals, groups, statutory bodies or organisations and health professionals in which all sides come together to discuss issues and feasible solutions and agree upon a course of action with the objective of achieving equity, efficiency and people’s empowerment in health development [31]. Some models are more specifically focused on consultation within the general practice setting, to promote quality improvement, whilst others have a wider remit across primary health care services and include consultation with, and needs analyses of, communities. The implicit assumptions are that communities know best their own health needs; there exists within communities, skills and knowledge required to play an effective role in health development and there is

genuine commitment on the part of health service staff to promote participation. The methods vary within and across countries and there is no one size fits all approach as the needs of communities vary. Indeed Rifkin argues that it is not realistic to propose any single model for managing community participation in health programmes [43]. There is a paucity of rigorous studies of these methods to determine their efficacy. A review of the literature of deliberative methods in the health sector identified only one systematic attempt to evaluate a particular method—the citizens' jury [101].

Some other challenges can be surmised about these deliberative methods to enact participation. Issues of power, invited spaces and representation, are cited frequently in the literature which hamper community participation. For example, it is expected that community members, who either self-select or are appointed, are able to set aside their individual interests and develop a shared vision for beneficial community outcomes. A criticism of community participation methods is that one group (often endogenous and usually the more powerful) tries to 'engage' the other group using its own processes [21, 36]. Power imbalances [21, 25, 55, 86, 102, 103] which exclude lay people from strategic decision-making processes and the inflexible use of existing management structures [25, 55, 102] all pose a threat to successful participation. Efforts to structure community participation in health become enmeshed in local politics and power struggles of interest groups can destabilise the participatory process [104] and can result in a kind of 'pseudo participation' [30]. Furthermore, getting involved in a process is not equivalent to having a voice [36]. Translating voice into influence requires more than capturing what people want to say - it involves efforts from above (those implementing policy) and below (those in receipt of policy initiatives or services). So opening spaces for dialogue is by no

means sufficient to ensure effective participation [36]. There is also a risk that such methods may be presented in a format and language that makes sense to one group but can alienate others. Essentially these methods represent what Cornwall [36] describes and criticises as ‘invited spaces’ (the creation of opportunities for participation orchestrated by an external agency, state or non-governmental body [36]). She highlights that, no matter how participatory groups seek to be, they are ‘still structured and owned by those who provide them’ as compared to spaces that people create for themselves thus consolidating the power of professionals rather than achieving the idea of broad based local involvement [21, 40].

Underlying this concern are issues of participant selection (given the amount of time required to participate and whether paid or volunteer) and, as mentioned above, representation (i.e., can such a small group of participants ever adequately represent the range of views at a local community, regional or national level?) [86]. Who really represents ‘the community’ is debatable [21]. The methods used to select community representatives and the degree to which they represent local issues are crucial to the perceived legitimacy of the representatives in the eyes of the population served. However, determining who is a legitimate representative of the community is far from straightforward [36, 40, 86]. So, assessing the extent to which the processes of community participation are legitimate, reasonable, responsive and fair are fundamental questions. This is especially true for a team-based setting where health professionals and community representatives are expected to work together with the intention of advancing the health and wellbeing of the collective. How this happens in practice and the legitimacy of the input of community is unclear [86]. Thus, evaluating process and interpersonal aspects of the work as well as outcomes

are important and remain largely unexamined. Therefore, it is important to build the evidence base about levers and barriers to implementation of community participation initiatives in practice this is addressed in the next section.

### **2.3.3 Implementing community participation in primary health care**

Whilst health policy espouses community participation as an ideal, implementation of community participation has proved problematic and how it is operationalized and sustained in practice is not well understood [14, 42, 105]. Predisposing conditions for implementing community participation in health include a political climate which accepts and supports active community participation and where policy legislation and resource allocation take account of regional and local needs [31, 40, 55, 103]. People who have previously participated in community activities are more willing to spend time on participation in primary health care [94] and trusting relationships between participants support community participation [42, 55]. Goals and expectations with respect to participation must be mutually identified and accepted [40]. If deliberate methods are to succeed, there needs to be buy-in at community level especially by civic leaders to mobilise citizen deliberation [86]. Additionally, effort and time is needed to provide clarity on roles and expectations of community participants [40, 88, 106-108] and to train and support workers [31, 109]. Lack of infrastructure, and lack of skills or confidence in organisations pose a barrier to community participation [13, 41, 86].

However, there is limited data across the multiplicity of stakeholder perspectives on implementing community participation in primary health care in practice and community perspectives are rarely captured [37]; data is usually from the perspective

of professionals or health policy actors (see [110]) . This hampers implementation because it is important to understand all stakeholders' perspectives. Motivations across stakeholders vary and rewards for community participants are largely philosophical, emotional and symbolic compared to health professionals and managers for whom participation often has tangible professional and career advantages [40]. To address these issues, boundary spanners have been identified in the literature as crucial to creating collaborative dynamic and supporting and implementing community participation initiatives.

Community workers employed in the main by community development organisations have been identified in the literature as “boundary spanners” [42, 52, 80, 110, 111] to denote local people who become advocates and translate and mediate between local people and professionals [27, 42, 52, 60, 80, 110]. This job is not just a technical one relating to ideas and resources, but a personal and political one [112], requiring skills in communication, listening, empathy, negotiation, consensus building and conflict resolution, helping to articulate the frames of many different actors, and interpreting those frames in the context of collective action [112]. Pertinent to the primary health care literature, Petchey et al. [113], extended the role described by Lipsky as “street-level bureaucrat” [114], to one of “street-level policy entrepreneurs” to emphasise their proactive and facilitative role in developing local primary health care (cancer care) innovations, characterised as having a strong community orientation, being champions, having inter-organisational and cross-sectoral knowledge and experience, an ability to network, and being flexible and proactive in terms of influencing and lobbying [112].

### 2.3.4 Community participation with marginalised groups

Despite a growing interest in the tools and indicators for evaluating the impact and outcomes of community participation as discussed earlier, few efforts have been made to explore the *process* of community participation with marginalized populations [110, 115]. There is evidence that community participation with marginalised groups poses some particular challenges.

Marginalised groups have been defined as ‘populations outside of “mainstream society”’ [116] and ‘highly vulnerable populations that are systemically excluded from national or international policy making forums’ [117]. Groups commonly described as such include; homeless people, drug users, sex workers, refugees, and ethnic minorities. Many of these groups experience severe health inequities and face significant barriers to accessing high-quality healthcare [118-122]. Consequently, members of these groups often have poorer health status than the general population and inadequate primary health care coverage [120, 123-127] and experience many barriers to accessing primary health care relating to health systems [128-133], patient factors [119, 120, 134-138], legal issues [119, 139, 140] and language barriers [140-143]. The issues of power, invited spaces and representation, discussed above are particularly challenging for marginalised groups [36, 144-146]. Such barriers mean it is also rare for these groups to be invited to participate in activities focused on the **planning** of primary health services and, therefore, **implementation** and **embedding** of community participation with these groups remains a challenge. It is important to adapt healthcare services so that they are culturally appropriate and sensitive to the

needs of the patient [147, 148]. Excluding marginalised groups from participating in primary health care may neglect alternative understandings about health and health care weakening capacity to promote change [149]. However, engaging marginalized populations involves addressing several layers of barriers related to marginalization and the associated social and cultural characteristics of marginalized populations [110].

Research with and for members of marginalised groups about their health care needs is vital to ‘give them voice’ and generate knowledge that informs policy and practice [122, 147, 148, 150, 151]. Simply creating opportunities however, to involve marginalized populations does not necessarily mean they will decide to participate [110]. Gaps in our knowledge of implementing community participation initiatives with marginalised groups need to be addressed, such as how maximum participation without delegation of resources or democratisation of power or understanding of representation may marginalise those communities and members further.

Understanding, negotiating and contesting power and the characteristics of spaces that can achieve empowerment and facilitate transformation remains an area which requires further research with these groups [41, 44, 103, 144].

#### **2.4 Policy Research, Implementation theory and Normalisation Process Theory (NPT) as an underpinning theory**

Health policies such as those about community participation in primary health care can be seen as the formal rules and guidelines about what actions are deemed necessary to strengthen the health system and improve health, translated through the

decision making of policy actors (middle managers, health workers, patients and citizens) into their daily practices [152].

#### **2.4.1 Health Policy and Health Policy and Systems Research:**

Health Policy and Systems Research (HPSR) is defined as a multidisciplinary field that seeks to understand and improve how societies organise themselves in achieving collective health goals and how different actors or how variations between settings interact in the policy and implementation processes to contribute to policy outcomes [152]. Covering international, national and local issues [152], it can be used retrospectively and prospectively to understand past policy failures and successes and to plan for future policy implementation [153]. However, there has been less attention given to how to do policy analysis and what research designs, theories or methods best inform policy analysis [153]. One challenge is the many hurdles to accessing the many different actors, individuals, groups and networks involved in the policy process [153]. There is also a tension between the long-term nature of policy development and implementation and the short term nature of both funding for policy research and the demands to researchers for quick answers and remedies [153]. Other conceptual challenges to ‘doing’ policy analysis include capturing and measuring different levels of resources, values, beliefs and power of diverse actors. Most health policy analysis is relatively intuitive, ad hoc and the assumptions on which it is based are seldom identified [153].

### **2.4.2 Implementation research to explore HPSR**

Implementation research is one approach to overcome these challenges. It has been defined as *“the scientific inquiry into questions concerning implementation—the act of carrying an intention into effect, which in health research can be policies, programmes, or individual practices (collectively called interventions)”* [154]p.1. It includes the study of influences on health care professional and organisational behaviour [155] and the study of changing behaviour and maintaining change. Therefore, the impact of context on implementation is important and the study of barriers or facilitators to implementation is needed [155].

### **2.4.3 Theory in Implementation Research**

The use of theory in implementation research offers three important potential advantages. They offer a generalisable framework that can apply across differing settings and individuals, they offer the opportunity for incremental accumulation of knowledge and they offer an explicit framework for analysis [155-158]. Using theory-led research designs to explain the implementation and integration of multifaceted interventions may inform the development of strategies to embed their use in practice [159]. Poor theoretical underpinning makes it difficult to understand and explain how and why implementation succeeds or fails and limits opportunities to identify factors that predict the likelihood of implementation success.

A sociological theory, called Normalisation Process Theory (NPT), has been used to understand how far Patient and Public Involvement (PPI) has been embedded within health-care research in certain areas [160]. There has been limited use of theory to

study implementation of community participation in primary health care more broadly [161] but this work did not focus on community participation in interdisciplinary team working (PCTs) as in this thesis.

#### **2.4.4 NPT as implementation theory underpinning this PhD**

Normalisation Process Theory (NPT) [162] began life as a model, constructed on the basis of empirical studies of the implementation of new technologies [163] and was subsequently expanded and developed into a theory as the various constructs were defined [164]. The theory identifies four determinants of embedding (i.e. normalising) complex interventions in practice (coherence or sense making, cognitive participation or engagement, collective action and reflexive monitoring) and the relationships between these determinants or constructs [165]. According to the literature, NPT has the capacity to elucidate the details of small scale implementation work, but also, to elucidate the ways in which macro, meso and micro levels of action and interaction shape that work [162]. As a middle range theory, NPT has been increasingly applied to many different healthcare specialities and contexts, including mental health, allied health, acute healthcare and primary healthcare settings as an explanatory model to guide the development and implementation of complex interventions [159]. The use of NPT in this study was deemed useful as a study of implementation of community participation on PCTs so that exploration of levers and barriers to this way of working could be generalised across other primary health care settings. The rationale for selecting it as the theory for this PhD study, a comparison with other theories and the details of the constructs, will be further presented in Chapter 3.

## **2.5 Summary of the Literature**

The concept of community participation is complicated by multiple definitions, terms and meanings. This conceptual ambiguity and the various typologies and frameworks to evaluate and implement community participation and lack of theoretical underpinnings for implementation makes evaluating the effectiveness of community participation difficult. Positive outcomes of community participation initiatives are reported in the literature but direct comparisons across studies and across initiatives are problematic.

Deliberative democracy processes have been employed internationally to enact community participation in primary health care. Methods vary widely as do the needs of communities. Challenges persist with these methods and viewing only some forms of community participation as legitimate is problematic. Despite the international policy idealism for community participation in primary health care, there are problems documented in the literature about implementing community participation in practice. Problems described include issues of power, representation and context. There is a lack of involvement of marginalised groups compounding these issues. There is also a lack of theoretically informed analysis of implementation processes. Therefore, comparison of methods to enact community participation are difficult. The use of NPT in this study was deemed useful to study implementation of community participation on PCTs so that exploration of levers and barriers to this way of working could be generalised across other primary health care settings.

## 2.6 References

1. Tierney, E., et al., *A critical analysis of the implementation of service user involvement in primary care research and health service development using normalization process theory*. Health Expectations, 2016. **19**(3): p. 501-515.
2. WHO, *Primary Health Care. Report of the international conference on primary health care*. 1978, WHO: Geneva
3. Charles, C.D., S., *Lay participation in health care decision-making: a conceptual framework*. Journal of Health Politics, Policy and Law 1993. **18**(4): p. 881-904.
4. Health Council of Canada, *Teams in Action Primary Health Care Teams for Canadians*. 2009, Health Council of Canada: Toronto
5. Department of Health, *Involving patients and the public in healthcare: response to the listening exercise*, Department of Health, Editor. 2001, UK Department of Health: London.
6. Department of Health and Children, *Primary Care: A New Direction*. 2001, Department of Health and Children: Dublin.
7. WHO, *Primary Health Care: Now More Than Ever*. 2008, WHO Geneva
8. Neuwelt P.M., *Community participation in primary care: what does it mean 'in practice'?* Journal of Primary Health Care., 2012. **4**(1): p. 30-8.
9. Welsh Government, *Parliamentary Review of Health and Social Care in Wales Interim Report*. 2017, Welsh Government.
10. Welsh Government, *Our plan for a primary care service for Wales up to March 2018*. 2014, Welsh Government.

11. Scottish Health Council, *Promoting, supporting and developing public involvement in primary care* 2013, The Scottish Health Council.
12. Morgan, L.M., *Community participation in health: perpetual allure, persistent challenge*. Health Policy and Planning, 2001. **16**(3): p. 221-230.
13. Sarrami-Foroushani, P., et al., *Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review*. BMC Health Services Research, 2014. **14**(1): p. 402.
14. Draper, A.K., G. Hewitt, and S. Rifkin, *Chasing the dragon: developing indicators for the assessment of community participation in health programmes*. Social Sci Med, 2010. **71**.
15. WHO, *Astana declaration on primary health care*. 2018, WHO: Geneva.
16. De Maeseneer, J., et al., *From 'patient' to 'person' to 'people': the need for integrated, people-centered healthcare*. International Journal of Person Centered Medicine, 2012. **2**(3): p. 601-614.
17. De Maeseneer, J., et al., *Primary health care as a strategy for achieving equitable care: a literature review commissioned by the Health Systems Knowledge Network*. 2007.
18. O'Reilly, P., et al., *Assessing the facilitators and barriers of interdisciplinary team working in primary care using normalisation process theory: an integrative review*. PLoS One, 2017. **12**(5): p. e0177026.
19. Xyrichis, A. and K. Lowton, *What fosters or prevents interprofessional teamworking in primary and community care? A literature review*. International Journal of Nursing Studies, 2008. **45**(1): p. 140-153.
20. Beresford, P. and S. Carr, *Social care, service users and user involvement*. Aotearoa New Zealand Social Work, 2016. **28**(2): p. 95.

21. Kenny, A., et al., *Community participation for rural health: a review of challenges*. Health Expectations, 2015. **18**(6): p. 1906-1917.
22. Sarrami-Foroushani, P., et al., *Key concepts in consumer and community engagement: a scoping meta-review*. BMC Health Serv Res, 2014. **14**(1): p. 250.
23. Conklin, A., Z. Morris, and E. Nolte, *What is the evidence base for public involvement in health-care policy?: results of a systematic scoping review*. Health Expectations, 2015. **18**(2): p. 153-165.
24. Rifkin, S.B., *A framework linking community empowerment and health equity: it is a matter of CHOICE*. Journal of Health, Population and Nutrition, 2003: p. 168-180.
25. Popay, J., *Community engagement and community development and health improvement: A background paper for NICE*. 2006, NICE London.
26. Taylor, J., D. Wilkinson, and B. Cheers, *Is it consumer or community participation? Examining the links between 'community' and 'participation'*. Health Sociology Review, 2006. **15**(1): p. 38-47.
27. Taylor, J., et al., *Community and health sector partnerships for primary prevention in Australia: Developing a typology*. Current Sociology, 2012. **60**(4): p. 506-521.
28. Wilkinson, K.P., *The community in rural America*. 1991: Greenwood Publishing Group.
29. Rifkin, S.B., F. Muller, and W. Bichmann, *Primary health care: on measuring participation*. Social Science & Medicine, 1988. **26**(9): p. 931-940.

30. Bath, J. and J. Wakerman, *Impact of community participation in primary health care: what is the evidence?* Aust J Prim Health, 2013.
31. Kahssay, H.M., P. Oakley, *Community involvement in health development: a review of the concept and practice.* 1999, WHO: Geneva.
32. WHO, *Community participation in local health and sustainable development: approaches and techniques.* 2002, WHO: Geneva.
33. Rifkin, S., G. Lewando-Hundt, and A. Draper, *Participatory approaches in health planning and promotion: a literature review.* London: Health Development Agency, 2000.
34. Attree, P., et al., *The experience of community engagement for individuals: a rapid review of evidence.* Health & Social Care in the Community, 2011. **19**(3): p. 250-260.
35. Farmer, J., et al., *Citizen participation in health services co-production: a roadmap for navigating participation types and outcomes.* Aust J Prim Health, 2018. **23**(6): p. 509-515.
36. Cornwall, A., *Unpacking 'Participation': models, meanings and practices.* Community Development Journal, 2008. **43**(3): p. 269-283.
37. Preston, R., et al., *Community participation in rural primary health care: intervention or approach?* Aust J Prim Health, 2010. **16**(1): p. 4-16.
38. Laverack, G., *Health promotion practice: building empowered communities.* 2007: McGraw-Hill Education (UK).
39. Taylor, J., D. Wilkinson, and B. Cheers, *Community participation in organising rural general practice: Is it sustainable?* Australian Journal of Rural Health, 2006. **14**(4): p. 144-147.

40. Zakus, J.D.L. and C.L. Lysack, *Revisiting community participation*. Health Policy and Planning, 1998. **13**(1): p. 1-12.
41. George, A.S., et al., *Community participation in health systems research: a systematic review assessing the state of research, the nature of interventions involved and the features of engagement with communities*. PLoS One, 2015. **10**(10): p. e0141091.
42. Taylor, J., et al., *Implementation of oral health initiatives by Australian rural communities: Factors for success*. Health & Social Care in the Community, 2018. **26**(1): p. e102-e110.
43. Rifkin, S.B., *Lessons from community participation in health programmes: a review of the post Alma-Ata experience*. Int Health, 2009. **1**(1): p. 31-36.
44. Montesanti, S.R., et al., *The value of frameworks as knowledge translation mechanisms to guide community participation practice in Ontario CHCs*. Social Science & Medicine, 2015. **142**: p. 223-231.
45. Arnstein, S.R., *A Ladder Of Citizen Participation*. Journal of the American Institute of Planners, 1969. **35**(4): p. 216-224.
46. Hart, R.A., *Stepping back from 'The ladder': Reflections on a model of participatory work with children*, in *Participation and learning*. 2008, Springer. p. 19-31.
47. Tritter, J.Q. and A. McCallum, *The snakes and ladders of user involvement: moving beyond Arnstein*. Health Policy, 2006. **76**(2): p. 156-168.
48. Gibson, A., N. Britten, and J. Lynch, *Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement*. Health, 2012. **16**(5): p. 531-547.

49. Popay, J., *Community engagement for health improvement. Questions of definition, outcomes and evaluation: Background paper prepared for NICE.* 2006, NICE London.
50. Abelson, J., *Understanding the role of contextual influences on local health-care decision making: case study results from Ontario, Canada.* *Social Science & Medicine*, 2001. **53**(6): p. 777-793.
51. McEvoy, R. and A. MacFarlane, *Community participation in primary care in Ireland: the need for implementation research.* *Primary Health Care Res*, 2013. **14**(02): p. 126-139.
52. Taylor, J., et al., *A Role for Communities in Primary Prevention of Chronic Illness? Case Studies in Regional Australia.* *Qualitative Health Research*, 2013. **23**(8): p. 1103-1113.
53. Kenny, A., et al., *Community participation in rural health: a scoping review.* *BMC Health Services Research*, 2013. **13**(1): p. 64.
54. Milton, B., et al., *The impact of community engagement on health and social outcomes: a systematic review.* *Community Development Journal*, 2011. **47**(3): p. 316-334.
55. Hoon Chuah, F.L., et al., *Community participation in general health initiatives in high and upper-middle income countries: A systematic review exploring the nature of participation, use of theories, contextual drivers and power relations in community participation.* *Social Science & Medicine*, 2018. **213**: p. 106-122.
56. NICE, *Community Engagement: Improving Health and Wellbeing and Reducing Health Inequalities.* 2016.

57. Crawford, M.J., et al., *Systematic review of involving patients in the planning and development of health care*. *BMJ*, 2002. **325**(7375): p. 1263.
58. Kearns, R. and P. Neuwelt, *Within and beyond clinics: Primary health care and community participation*. *Primary health care: people, practice, place*. Farnham, Burlington VT: Ashgate, 2009: p. 203-20.
59. Wallerstein, N., *What is the evidence on effectiveness of empowerment to improve health?*. Copenhagen, World Health Organization [WHO], Regional Office for Europe, Health Evidence Network, 2006 Feb. 37 p. (Health Evidence Network Report).
60. Neuwelt, P., et al., *Assessing and developing community participation in primary health care in Aotearoa New Zealand: a national study*. *New Zealand Medical Journal (Online)*, 2005. **118**(1218).
61. Farmer, J. and A. Nimegeer, *Community participation to design rural primary healthcare services*. *BMC Health Services Research*, 2014. **14**(1): p. 130.
62. Frankish, C.J., et al., *Challenges of citizen participation in regional health authorities*. *Social Science & Medicine*, 2002. **54**(10): p. 1471-1480.
63. Cornwall, A. and V.S. Coelho, *Spaces for change?: the politics of citizen participation in new democratic arenas*. Vol. 4. 2007: Zed Books.
64. Fearon, J.D., *Deliberation as Discussion*, in *Deliberative Democracy*, J. Elster, Editor. 1998, Cambridge University Press: Cambridge. p. 44-68.
65. Habermas, J., *The theory of communicative action*. Vol. 2. 1984: Beacon press.
66. Bostwick, M., *Twelve Angry Citizens: Can Citizens' Juries Improve Local Democracy in New Zealand?* *Political Science*, 1999. **50**(2): p. 236-246.

67. Consortium, D.D. 2018; Available from: <http://deliberative-democracy.net> accessed June 8th 2018
68. Carson, L. and J. Hartz-Karp, *Adapting and combining deliberative designs: Juries, polls, and forums*. The deliberative democracy handbook: Strategies for effective civic engagement in the Twenty-First Century, 2005: p. 120-138.
69. Carpini, M.X.D., F.L. Cook, and L.R. Jacobs, *Public deliberation, discursive participation, and citizen engagement: A review of the empirical literature*. Annu. Rev. Polit. Sci., 2004. **7**: p. 315-344.
70. Department of Health, *Local voices*, NHSME, Editor. 1992: London.
71. Ruano, A.L., M.S. Sebastián, and A.K. Hurtig, *The process of social participation in primary health care: the case of Palencia, Guatemala*. Health Expectations, 2014. **17**(1): p. 93-103.
72. Barry , M.J. and S. Edgman-Levitan *Shared decision making — The pinnacle of patient-centered care*. New Eng Med, 2012. **366**(9): p. 780-781.
73. Gooberman-Hill, R., J. Horwood, and M. Calnan, *Citizens' juries in planning research priorities: process, engagement and outcome*. Health Expectations., 2008. **11**(3): p. 272-281.
74. Brown, I., *Patient participation groups in general practice in the National Health Service*. Health Expectations, 1999. **2**(3): p. 169-178.
75. Wilkie, P., *Patient participation groups in general practice: building better partnerships*. 2016, Brit Gen Pract. p. 548-549.
76. Coulter, A., *Patient engagement—what works?* Ambul Care Maanage, 2012. **35**(2): p. 80-89.
77. Department of Health, *The NHS Plan*. 2000, HMSO: London.

78. Department of Health, *Patient and public involvement in the NHS* 1999, UK Department of Health: London.
79. Department of Health, *Department of Health; NHS and Social Care Act*, Department of Health, Editor. 2001, HMSO: London.
80. Anderson, E., M. Shepherd, and C. Salisbury, '*Taking off the suit*': *engaging the community in primary health care decision-making*. *Health Expectations*, 2006. **9**(1): p. 70-80.
81. Box, G., *Patient participation groups: the national picture*. *Quality in Primary Care*, 2009. **17**(4): p. 291-297.
82. Gillam, S. and J. Newbould, *Patient participation groups in general practice: what are they for, where are they going?* *BMJ*, 2016. **352**.
83. Greco, M., et al., *Impact of patient involvement in general practice*. *Education for Primary Care*, 2006. **17**(5).
84. O'Shea, A., M. Chambers, and A. Boaz, *Whose voices? Patient and public involvement in clinical commissioning*. *Health Expectations*, 2016. **20**: p. 484–494.
85. Serapioni, M. and N. Duxbury, *Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees*. *Health Expectations*, 2014. **17**(4): p. 488-499.
86. Abelson, J., et al., *Deliberations about deliberative methods: issues in the design and evaluation of public participation processes*. *Social Science & Medicine*, 2003. **57**(2): p. 239-251.
87. Pollard, L., et al., *The impact of patient participation direct enhanced service on patient reference groups in primary care: a qualitative study*. *Quality in Primary Care*, 2014. **22**(4): p. 189-199.

88. Nathan, S., L. Johnston, and J. Braithwaite, *The role of community representatives on health service committees: staff expectations vs. reality*. *Health Expectations*, 2011. **14**(3): p. 272-284.
89. Department of Health and Ageing, *Building a 21st Century Primary Health Care System: A Draft of Australia's First National Primary Health Care Strategy*. 2009, Commonwealth of Australia: Canberra
90. Hartz-Karp, J., *How and why deliberative democracy enables co-intelligence and brings wisdom to governance*. *Journal of Public Deliberation*, 2007. **3**(1): p. 6.
91. King, H.A., *The primary health care strategy*. 2001, Ministry of Health: Wellington.
92. Ministry of Health, *Minimum requirements for Primary Health Organisations*, Ministry of Health, Editor. 2001: Wellington.
93. Maxwell, J., S. Rosell, and P.-G. Forest, *Giving citizens a voice in healthcare policy in Canada*. *BMJ: British Medical Journal*, 2003. **326**(7397): p. 1031.
94. Kroneman, M., K. van Erp, and P. Groenewegen, *Community participation in primary care: willingness to participate, a web survey in the Netherlands*. *Primary Health Care Research & Development*, 2018: p. 1-7.
95. Van de Bovenkamp, H.M., M.J. Trappenburg, and K.J. Grit, *Patient participation in collective healthcare decision making: the Dutch model*. *Health Expectations*, 2010. **13**(1): p. 73-85.
96. Kringos, D.S., et al., *Building primary care in a changing Europe. Case studies*. 2015: WHO Regional Office for Europe.

97. Rawaf, S., J. De Maeseneer, and B. Starfield, *From Alma-Ata to Almaty: a new start for primary health care*. The Lancet, 2008. **372**(9647): p. 1365-1367.
98. Rhyne, R., et al., *Community Oriented Primary Care: health care for the 21st century*. 1998.
99. Art, B., et al., *An interdisciplinary community diagnosis experience in an undergraduate medical curriculum: development at Ghent University*. Academic Medicine, 2008. **83**(7): p. 675-683.
100. Maeseneer, J.D. and A. Derese, *Community-oriented primary care*. The European Journal of General Practice, 1998. **4**(2): p. 49-50.
101. McIver, S., *Healthy Debate?: An Independent Evaluation of Citizens' Juries in Health Settings*. 1998: King's Fund.
102. Pickin, C., et al., *Developing a model to enhance the capacity of statutory organisations to engage with lay communities*. Journal of Health Services Research & Policy, 2002. **7**(1): p. 34-42.
103. Rifkin, S.B., *Lessons from community participation in health programmes*. Health Policy and Planning, 1986. **1**(3): p. 240-249.
104. Stone, L., *Cultural influences in community participation in health*. Social Science & Medicine, 1992. **35**(4): p. 409-417.
105. Meier, B.M., C. Pardue, and L. London, *Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa*. BMC International Health and Human Rights, 2012. **12**(1): p. 15.

106. Fudge, N., C.D. Wolfe, and C. McKeivitt, *Assessing the promise of user involvement in health service development: ethnographic study*. *BMJ*, 2008. **336**(7639): p. 313-317.
107. Hogg, C. and C. Williamson, *Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees*. *Health Expectations*, 2001. **4**(1): p. 2-9.
108. Hogg, C.N., *Patient and public involvement: what next for the NHS?* *Health Expectations*, 2007. **10**(2): p. 129-138.
109. Freeman, T., et al., *Service providers' views of community participation at six Australian primary healthcare services: scope for empowerment and challenges to implementation*. *The International Journal of Health Planning and Management*, 2016. **31**(1): p. E1-E21.
110. Montesanti, S.R., et al., *Enabling the participation of marginalized populations: case studies from a health service organization in Ontario, Canada*. *Health Promotion International*, 2016. **32**(4): p. 636-649.
111. Detmer, D., *Clinician-managers: the 'boundary spanners' of health services*. *J Health Serv Res Pol*, 2000. **5**: p. 197-198.
112. Williams, P., *We are all boundary spanners now?* *International Journal of Public Sector Management*, 2013. **26**(1): p. 17-32.
113. Petchey, R., J. Williams, and Y.H. Carter, *From Street-level Bureaucrats to Street-level Policy Entrepreneurs? Central Policy and Local Action in Lottery-funded Community Cancer Care*. *Social Policy & Administration*, 2008. **42**(1): p. 59-76.
114. Lipsky, M., *Street-Level Bureaucracy, 30th Ann. Ed.: Dilemmas of the Individual in Public Service*. 2010: Russell Sage Foundation.

115. Baatiema, L., et al., *Assessing participation in a community-based health planning and services programme in Ghana*. BMC Health Services Research, 2013. **13**(1): p. 233.
116. Schiffer K, S.E., *Marginalisation, social inclusion and health*. 2008, Foundation Regenboog AMOC & Correlation Network: Amsterdam.
117. Siddiqui, F.R., *Annotated bibliography on participatory consultations to help aid the inclusion of marginalized perspectives in setting policy agendas*. International Journal for Equity in Health, 2014. **13**(1): p. 124.
118. O'Donnell, C.A., et al., *Reducing the health care burden for marginalised migrants: the potential role for primary care in Europe*. Health Policy, 2016. **120**(5): p. 495-508.
119. Islam, M.M., et al., *The accessibility, acceptability, health impact and cost implications of primary healthcare outlets that target injecting drug users: a narrative synthesis of literature*. International Journal of Drug Policy, 2012. **23**(2): p. 94-102.
120. All Ireland Traveller Health Study Team, *All Ireland Traveller Health Study: Our Geels – Summary of findings*. 2010, School of Public Health, Physiotherapy and Population Science, University College Dublin: UCD.
121. Dixon-Woods M, A.S., Kirk D., *Vulnerable groups and access to health care: a critical interpretive review*. 2005, National Co-ordinating Centre for NHS Service Delivery and Organisation: University of Leicester, United Kingdom.
122. van den Muijsenbergh, M., et al., *Giving voice to the voiceless: how to involve vulnerable migrants in healthcare research*. British Journal of General Practice, 2016. **66**(647): p. 284-285.

123. Story, A., *Slopes and cliffs in health inequalities: comparative morbidity of housed and homeless people*. The Lancet, 2013. **382**: p. S93.
124. O'Reilly F, B.S., Hannigan A, Scriver S, Ruane L, MacFarlane A, et al. , *Homelessness: an unhealthy state – Health status, risk behaviours and service utilisation among homeless people in two Irish cities*. 2015, Partnership for Health Equity.
125. Balfour R, A.J., *A review of the literature on sex workers and social exclusion*. 2014, Institute of Health Equity University College London.
126. Dias, S., et al., *Healthcare-seeking patterns among immigrants in Portugal*. Health & Social Care in the Community, 2011. **19**(5): p. 514-521.
127. Schoevers, M.A., et al., *Health care utilisation and problems in accessing health care of female undocumented immigrants in the Netherlands*. International Journal of Public Health, 2010. **55**(5): p. 421-428.
128. Woodward, A., N. Howard, and I. Wolffers, *Health and access to care for undocumented migrants living in the European Union: a scoping review*. Health Policy and Planning, 2013. **29**(7): p. 818-830.
129. Hudson, A.L., et al., *Health-seeking challenges among homeless youth*. Nursing Research, 2010. **59**(3): p. 212.
130. Edland-Gryt, M. and A.H. Skatvedt, *Thresholds in a low-threshold setting: an empirical study of barriers in a centre for people with drug problems and mental health disorders*. International Journal of Drug Policy, 2013. **24**(3): p. 257-264.
131. Nguyen, M.-N., et al., *Why and according to what consultation profiles do female sex workers consult health care professionals? A study conducted in*

- Laval, Québec*. Health Care for Women International, 2008. **29**(2): p. 165-182.
132. Williamson, D.L., et al., *Low-income Canadians' experiences with health-related services: implications for health care reform*. Health Policy, 2006. **76**(1): p. 106-121.
133. Loignon, C., et al., *Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project*. International Journal for Equity in Health, 2015. **14**(1): p. 4.
134. Wen, C.K., P.L. Hudak, and S.W. Hwang, *Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters*. Journal of General Internal Medicine, 2007. **22**(7): p. 1011-1017.
135. Nickasch, B. and S.K. Marnocha, *Healthcare experiences of the homeless*. Journal of the American Academy of Nurse Practitioners, 2009. **21**(1): p. 39-46.
136. Asgary, R. and N. Segar, *Barriers to health care access among refugee asylum seekers*. Journal of Health Care for the Poor and Underserved, 2011. **22**(2): p. 506-522.
137. Neale, J., C. Tompkins, and L. Sheard, *Barriers to accessing generic health and social care services: a qualitative study of injecting drug users*. Health & Social Care in the Community, 2008. **16**(2): p. 147-154.
138. McGorrian C, F.K., Daly L, Moore RG, Turner J, Sweeney MR, et al, *The health care experiences of Travellers compared to the general population: the All-Ireland Traveller Health Study*. Journal of Health Services Research & Policy, 2012. **17**(3): p. 173-180.

139. Campbell, R.M., et al., *A comparison of health access between permanent residents, undocumented immigrants and refugee claimants in Toronto, Canada*. *Journal of Immigrant and Minority Health*, 2014. **16**(1): p. 165-176.
140. Biswas, D., et al., *Access to healthcare and alternative health-seeking strategies among undocumented migrants in Denmark*. *BMC Public Health*, 2011. **11**(1): p. 560.
141. Folch, C., et al., *Female sex workers and access to social and health services in Catalonia: Influence of region of origin and place of work*. *AIDS care*, 2013. **25**(8): p. 1033-1038.
142. Newbold, K.B., J. Cho, and M. McKeary, *Access to Health care: the experiences of refugee and refugee claimant women in Hamilton, Ontario*. *Journal of Immigrant & Refugee Studies*, 2013. **11**(4): p. 431-449.
143. MacFarlane, A., et al., *Arranging and negotiating the use of informal interpreters in general practice consultations: experiences of refugees and asylum seekers in the west of Ireland*. *Social Science & Medicine*, 2009. **69**(2): p. 210-214.
144. de Freitas, C. and G. Martin, *Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare*. *Social Science & Medicine*, 2015. **135**: p. 31-39.
145. El Enany, N., G. Currie, and A. Lockett, *A paradox in healthcare service development: Professionalization of service users*. *Social Science & Medicine*, 2013. **80**: p. 24-30.

146. Martin, G.P., *Representativeness, legitimacy and power in public involvement in health-service management*. *Social Science & Medicine*, 2008. **67**(11): p. 1757-1765.
147. MacFarlane, A., et al., *Healthcare for migrants, participatory health research and implementation science—better health policy and practice through inclusion. The RESTORE project*. *The European Journal of General Practice*, 2014. **20**(2): p. 148-152.
148. Lionis, C., et al., *Assessing refugee healthcare needs in Europe and implementing educational interventions in primary care: a focus on methods*. *BMC International Health and Human Rights*, 2018. **18**(1): p. 11.
149. de Freitas, C., *Aiming for inclusion: a case study of motivations for involvement in mental health-care governance by ethnic minority users*. *Health Expectations*, 2015. **18**(5): p. 1093-1104.
150. O'Reilly-de Brún, M., et al., *Involving migrants in the development of guidelines for communication in cross-cultural general practice consultations: a participatory learning and action research project*. *BMJ Open*, 2015. **5**(9): p. e007092.
151. O'Reilly-de Brún, M., et al., *Using Participatory Learning & Action research to access and engage with 'hard to reach' migrants in primary healthcare research*. *BMC Health Services Research*, 2016. **16**(1): p. 25.
152. Gilson, L., *Health policy and systems research A Methodology Reader*. 2012.
153. Walt, G., et al., *'Doing' health policy analysis: methodological and conceptual reflections and challenges*. *Health Policy and Planning*, 2008. **23**(5): p. 308-317.

154. Peters, D.H., et al., *Implementation research: what it is and how to do it*. BMJ, 2013. **347**: p. f6753.
155. Eccles, M.P., et al., *An implementation research agenda*. Implementation Science, 2009. **4**(1): p. 18.
156. Damschroder, L.J. and J.C. Lowery, *Evaluation of a large-scale weight management program using the consolidated framework for implementation research (CFIR)*. Implementation Science, 2013. **8**(1): p. 51.
157. Nilsen, P., *Making sense of implementation theories, models and frameworks*. Implementation Science, 2015. **10**(1): p. 53.
158. Davidoff, F., et al., *Demystifying theory and its use in improvement*. BMJ Qual Saf, 2015: p. bmjqs-2014-003627.
159. Gillespie, B.M., et al., *Using normalisation process theory to evaluate the implementation of a complex intervention to embed the surgical safety checklist*. BMC Health Services Research, 2018. **18**(1): p. 170.
160. Wilson, P., et al., *ReseArch with Patient and Public involvement: a RealisT evaluation—the RAPPORT study*. Health Serv Deliv Res, 2015. **3**(38).
161. McEvoy, R., *National Strategy for Service User Involvement in the Irish Health Services: A Case Study Analysis of Policy Implementation*, in *Graduate Entry Medical School*. 2014, University of Limerick: Limerick
162. May, C. and T. Finch, *Implementing, embedding, and integrating practices: An outline of Normalization Process Theory*. Sociology, 2009. **43**(3): p. 535-554.
163. May, C., et al., *Understanding the implementation of complex interventions in health care: the normalization process model*. BMC Health Services Research, 2007. **7**(1): p. 148.

164. Finch, T.L., et al., *Improving the normalization of complex interventions: measure development based on normalization process theory (NoMAD): study protocol*. Implementation Science, 2013. **8**(1): p. 43.
165. Murray, E., et al., *Normalisation process theory: a framework for developing, evaluating and implementing complex interventions*. BMC Medicine, 2010. **8**(1): p. 63.

## **Chapter 3: Methodology**

### **3.1 Introduction**

This chapter covers some key methodological issues for this study. It is divided into five sections. Section 1 focuses on the study paradigm, ontology and epistemology, provides information about the design of the three projects which underpin this research and describes how they influenced the paradigmatic shaping of the thesis. Section 2 focuses on broader cross cutting methodological issues pertaining to ethical considerations across the three projects followed by section 3 describing the methodological approach and the research design of the study ; case study approach and mixed methods. In section 4, the theoretical foundation of the research is discussed and an outline of Normalisation Process Theory is presented. Finally, the approach to integrated data analysis across the three publications is described.

### **3.2 Part 1 Introduction: Ontology, Epistemology and Methodological Approach**

The term *paradigm* was popularized by Thomas Kuhn in 1962 [1]. He described it as a general concept that included a group of researchers having a common education and agreement of exemplars of high quality research or thinking [1]. It has also been defined as the '*basic belief system or world view that guides investigation*' [2]p.105 or as a *research culture* [3].

The question ‘what is reality?’ (ontology) and ‘how do we come to know it?’ (epistemology) has been posed by scholars across disciplines throughout history [4]. The researcher’s methodological approach is underpinned by and reflects specific ontological and epistemological beliefs and is concerned with techniques or procedures to collect and analyse data that can reflect these views. These beliefs are often shared by those working in a particular domain or tradition [2, 5]. Furthermore, the *assumptions* held by the researcher influences every aspect of the research process; for example the generating, analysing and reporting of research findings. The researcher’s *epistemological stance is concerned with ‘the possible ways of gaining knowledge of social reality, whatever it is understood to be’* [6]p8.

Until recently, there have been two primary but often competing views of social reality in health research and how to obtain knowledge. These two perspectives reflect the basic differences between naturalistic inquiry and experimental type research [4]. Referred to as positivist and interpretivist paradigms, they underlie quantitative and qualitative methods, respectively. Logical positivism is the foundation for deductive predictive designs referred to as quantitative experimental type research. Quantitative purists maintain that scientific inquiry should be objective and separate from time and context, generalisations are possible and causes of scientific outcomes can be determined reliably and validly [3]. In contrast, a number of holistic and humanist philosophical perspectives use inductive and abductive reasoning which form the foundation for the research tradition known as naturalistic enquiry associated with qualitative research [4]. This interpretive paradigm posits *that social reality is locally and specifically constructed by humans through their action and interaction* [2]p. 14. Interpretive researchers attempt to

understand and explain phenomena by accessing the meanings people assign to them [7]; social reality is influenced by culture and is situated in experiences through which people create subjective meanings as they interact with the world [8].

Paradigm purists argue for the '*incompatibility thesis*' [9] – that paradigms and their associated research methods cannot and should not be mixed [3]. These '*paradigm wars*' [3] have led to a focus on the differences between the two orientations and the two dominant research paradigms have resulted in two research cultures.

However, a third research paradigm has more recently emerged, known as pragmatism [4]. Pragmatism derives from the work of Murphy, Patton, Rorty and Cherryholmes [10-13]. Pragmatism is concerned with the application of what works or how to find solutions to problems [13] rather than focusing on methodological stance. As a philosophical underpinning, its importance lies in attention to the research problem and then using pluralistic approaches (mixed methods) to derive knowledge about the problem [13-16]. Pragmatism can be characterised as an '*unparadigm*,' [15]p.15, so it is tuned to the selection of methodological tools that are most purposive in solving a knowledge problem [15]. As the third research paradigm, it can also help bridge the schism between quantitative and qualitative research [3]. Today's research world is becoming increasingly interdisciplinary, complex and dynamic: therefore there is a need to combine and complement research methods which can promote communication and collaboration between researchers. Taking a non-purist approach to research can offer an opportunity to researchers to

mix and match design components that offer the best chance of answering specific research questions [3].

In this study, the ontological and epistemological stance of the PhD candidate was influenced by the apriori designs of the three projects outlined in Chapter 1, which underpin the study. These three projects had some defining features in that they were predominantly qualitative in nature (one study had a survey component). Two of the three project designs were theoretically informed by Normalisation Process Theory (NPT). All were designed with principles of participatory health research. This meant that from a PhD perspective, the work was not purely positivist or interpretive and resonated with the pragmatic approach [3, 17].

The key features of the pragmatic approach are, that it draws liberally from both quantitative and qualitative assumptions, focusing on what works to best answer the research question in the real world. It involves ‘messy’ research with practical and outcome oriented methods of enquiry to produce socially useful knowledge. Table 3.1 shows how these key features of a pragmatic approach resonate with this study.

**Table 3.1: Key features of a pragmatic approach to research and how these apply to the current study**

| <b>Key Features of the Pragmatic Approach</b>  | <b>Application to this Study</b>   |
|--|--|
| <p>Pragmatism is not committed to any one system of philosophy and reality, it draws liberally from both quantitative and qualitative assumptions as well as different forms of data collection and analysis [16]. Mixed methods research often provides a more workable solution and produces a superior product [3].</p> | <p>Quantitative and qualitative data were derived from three projects and combined data from an on-line national survey, focus groups and interviews to interrogate the concept of community participation on PCTs.</p>  |
| <p>Research approaches are mixed in ways that offer the best opportunities for answering important research questions [3]. It focuses on ‘what works’ to best answer the research question.</p>  | <p>Methods in the three projects were chosen to suit the needs of those wider projects, and when combined, suited the PhD study aim and objectives.</p>  |
| <p>Pragmatism is suitable for research grounded in the real world. It also enables researchers to enjoy the complexity and messiness of life [17].</p>   | <p>The research was situated in the real world exploring implementation of primary health care policy on the ground. Combining and extending data analysis across three projects offered an opportunity to explore phenomenon of community participation enacted on PCTs on the ground.</p>        |
| <p>It offers a practical and outcome oriented method of enquiry that is based on action and leads iteratively to further action and the elimination of doubt. It offers a method for selecting methodological mixes that can help researchers better answer many of their research questions [3].</p>                      | <p>This study used this practical approach to explore the levers and barriers to policy implementation. By extending and integrating data collected in three projects an opportunity was taken to explore a research question for this research which would otherwise not have been uncovered.</p> |
| <p>Pragmatism takes an explicitly value oriented approach to research; e.g., helping to reduce discrimination in society [3]. It is guided by the</p>  | <p>The use of Participatory Learning and Action (PLA) methods in two of the research projects had an explicit value oriented approach. Stakeholders had a voice during data generation and analysis in the three projects. By extending</p>  |

| Key Features of the Pragmatic Approach            | Application to this Study   |
|---|---|
| desire to produce socially useful knowledge [17]. | the analysis, data about how community representatives and patient voice can help shape primary health care services specifically through PCTs was uncovered. |

There is a strong argument that pragmatism is sometimes replaced by ‘practicalism’ [3]. It has been asked ‘for whom is the pragmatic solution useful?’ [18]. It was important to question if this stance merely suited the PhD candidate as a convenient way to extend and integrate data from three projects, or if it could be considered as the best approach to combine relevant data from the key data sources to illuminate the evidence for what was happening on the ground. Mapping the features of a pragmatic approach clearly demonstrates that this approach to the study of extending and integrating the analysis was more than merely a methodological approach of convenience and offered the opportunity to employ a methodological mix that could better answer a complex research question [3].

### 3.2.1 Other paradigmatic influences

Although the pragmatic paradigm was the main influence in this study, Participatory Health Research (PHR) as a research paradigm also influenced the PhD candidate’s thinking and methodological approach to this study. The key features of PHR as a research paradigm and the key influences are outlined below.

Participatory Health Research (PHR), as a research paradigm, means that participation is the defining principle throughout the research process. The

assumption is that participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research [19]. It thus provides a rich resource for conducting high quality research that includes Patient and Public Involvement (PPI) in health research. PHR produces forms of knowledge and action which make a unique and important contribution in addressing health issues (including health care provision) particularly issues related to the determinants of health and health inequalities. The goal is to provide the opportunity for all participants to be equitably involved throughout the research [19, 20] and to empower all members to engage actively in the process thus having control over the research.

There is agreement that PHR includes a wide spectrum of partnerships and end users may choose not to be involved at all stages and degree of involvement varies widely [21, 22]. At a minimum, PHR requires the co-development of the research question, interpretation of results and the crafting of messages and involvement in dissemination of findings [23]. As a research paradigm, it incorporates both qualitative and quantitative methods [19].

The minimum requirements for PHR projects as outlined by Salsberg [22] were met in this PhD study and are outlined in Table 3.2. Text in bold in the table indicates where there was academic involvement exclusively.

**Table 3.2: Participatory health research requirements in the three projects comprising the study**

| <b>Principles of PHR</b>  | <b>Application in this PhD study</b>   |
|---|--|
| Co-development of the research question   | <p>In the survey reported in PhD paper 1 (Chapter 4), the steering group comprised stakeholders including: health professionals, GPs, policy makers and academics who had input into the development of the research question for the grant.</p> <p>Community, health care and academic stakeholders who were members of Steering groups /Advisory groups were involved in the development of the research question for the grants leading to PhD papers 2 and 3 (Chapters 5 and 6).</p> <p><b>Academic involvement only in the development of the PhD question</b></p>  |
| All partners contribute appropriately to the interpretation of results  | <p>Patients/service users, community representatives, health professionals and academic researchers were involved in co-analysis of data in focus groups in two projects reported in PhD papers 2 and 3 (Chapters 5 and 6). The use of PLA techniques in data generation supported this.</p> <p>Feedback sessions with all participants in PhD Papers 2 and 3, (Chapters 5 and 6) were conducted to check findings and clarify interpretations, comment on generalisability and transferability of findings.</p> <p><b>Academic involvement only in the data integration, analysis and interpretation for the PhD study.</b></p> |
| <p>All partners contribute appropriately to the crafting of messages</p> <p>All partners contribute appropriately to dissemination of results</p> | <p>Community representatives in PhD Paper 2 (Chapter 5) were involved in dissemination activities feedback on a publication of A framework for community participation in primary health care [24], and presentation of their work with academic partners; on community participation in primary health care at a university/community conference.</p> <p>Input from key stakeholders in the write up of PhD Paper 1 (Chapter 4) for publication in peer- reviewed journal.</p> <p><b>Academic involvement only in the crafting of messages for the PhD data integration</b></p>   |

### **3.3 Ethical considerations across the three projects**

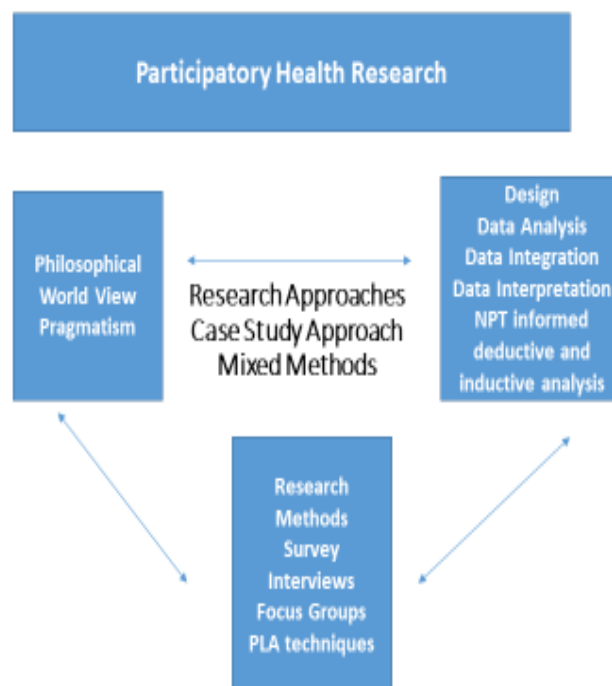
Ethical approval was received for each of the three projects from the Irish College of General Practitioners (ICGP) (See Appendix 3a). Throughout the conduct of the three projects and where required, revisions to our ethical procedures or advice from the ethics committee were sought. For example, during focus groups with marginalised groups in Paper 3 (Chapter 6), one member of the group died. We suspended focus groups out of respect for this person and the group and sought advice from the research ethics committee about the best way to proceed and how to address this (unrelated) tragedy in our subsequent research sessions. Participants were offered the opportunity to speak about the deceased participant or withdraw from the research if they wished. In Paper 2 (Chapter 5) we wished to photograph the PLA sessions conducted during fieldwork for use in dissemination and for research outputs and sought additional approval from the Chair of the ethics committee for this (See Appendix 3b).

As Senior Researcher on all three projects, the PhD Candidate had access to the data from all three projects for the integrated data analysis for this PhD. The integrated data analysis was the opportunity for an in-depth analysis that (i) constituted this PhD question and (ii) added depth to understanding about community participation on PCTs in each of the individual projects. Expanding on and developing data analysis from three projects already underway was deemed to be an ethical approach to uncovering data in a difficult to research area. The integrated analysis was conducted using knowledge of the key findings as presented in the three papers

(Chapters 4, 5 and 6). This process of further analysing findings reported in the papers (i.e., mapping them onto NPT constructs) did not require additional ethical approval thus minimising the potential for research burden or research fatigue. Analytical notes and reflective diaries were written up by the PhD candidate as a means to reflect on any ethical issues arising (See examples in Appendix 4).

### 3.4 Research Design: Case Study Approach

The research design for this study was a case study approach using mixed methods (See Figure 3.1).



**Figure 3.1: Framework for this research: Adapted from Creswell 2013 - A framework for research the interconnection of worldviews, design and research methods [16]**

Case study has been variously defined as a method, methodology or research design and is used as a catch all phrase for a variety of research methods, methodologies and designs and thus loses its meaning [25]. Yin suggests that the term case refers to an event, an entity, an individual or a unit of analysis. He describes case study as ‘*an empirical inquiry that investigates a contemporary phenomenon within its real life context using multiple sources of evidence especially when the boundaries between phenomenon and context are not clearly evident*’ (Yin, 2003, p. 13)[26]. Similarly, Creswell [16] describes a case study as ‘*a problem to be studied, which will reveal an in-depth understanding of a “case” or bounded system, which involves understanding an event, activity, process, or one or more individuals*’ (Creswell, 2002, p. 61)[16]. Stake [27], on the other hand, separates case study from methodology by stating; ‘*case study is not a methodological choice but a **choice** of what is to be studied*’ [27](p. 438). The researcher does not choose the case rather, the research process, and the interaction between case and unit of analysis, guides a choice of what is to be studied [27]. This definition calls for the researcher to start with a dilemma that will invoke layers of understanding about the system in which the problem resides. The system becomes the case, and then the researcher chooses an event, activity, or process within this system to illuminate it. Researchers employ various research methods which act to build or uncover the case. Despite the existence of many different types of case study, none of them require specific data collection procedures [25]. Quantitative as well as qualitative data can be part of the

same case study; most case studies will rely on multiple types of data collection. In using multiple sources of evidence, the goal during the data collection process is to accumulate converging evidence and to triangulate over a given fact [28].

In this study data was gathered employing quantitative and qualitative methods with various participant sources allowing the convergence and triangulation of data across multiple data sources and sites (See Table 3.3).

The survey was piloted with research co-applicants and collaborators who represented a number of the service provider professions of interest in this research i.e., practice nurse, general practitioners, occupational therapist, physiotherapist and speech and language therapists (N=10). Minor changes were made to the draft survey based on feedback following the pilot e.g., ordering and phrasing of questions. This helped us to clarify goals, flagged up potential practical problems e.g., length of questionnaire and time to complete.

The data from the survey was summarised using descriptive statistics i.e. count (percentage) for categorical data and median (first quartile, third quartile) for rating scales and rankings.

Cronbach's alpha was used as a measure of internal consistency of items related to progress of implementation and effectiveness of strategy and team working (Q2, Q3, Q8, and Q9 on the survey instrument). Non-parametric tests were used to compare median ratings across groups. A Mann-Whitney U test was used to compare medians across two groups and a Kruskal-Wallis test was used to compare medians across three groups. A 5% level of significance was used for all statistical tests. SPSS version 21 for Windows was used for the analysis.

**Table 3.3: Data sources: Participants and methods employed across the three studies N=629**

For the detail and breakdown of participant groups and methods across the three papers see Chapters 4, 5 and 6.

| Stakeholder  | Data source and method employed   | N in Paper       | N in overall PhD study |
|--|---|------------------|------------------------|
| Community representatives <sup>1</sup>   | Paper 2; Chapter 5<br>Qualitative study employing focus groups and interviews based on a participatory research approach and using PLA methods  | n=27             | n=27                   |
| Health Service Executive (HSE) health professionals and practitioners who are working on the PCTs <sup>2</sup>                           | Paper 1; Chapter 4<br>Quantitative study employing an online survey<br><br>Paper 2; Chapter 5<br>Qualitative study employing focus groups and interviews based on a participatory research approach and using PLA methods | n=473<br><br>n=4 | n=477 <sup>3</sup>     |
| HSE service planners and policy makers who oversee the development of PCTs and implementation of primary health care policy <sup>3</sup> | Paper 1; Chapter 4<br>Quantitative study employing an online survey<br><br>Paper 2; Chapter 5<br>Qualitative study employing focus groups and interviews based on a participatory research approach and using PLA methods | n=25<br><br>n=5  | n=30                   |
| GPs working with PCTs  | Paper 1; Chapter 4<br>Quantitative study employing an online survey   | n= 71            | n=74                   |

<sup>31</sup>Includes community representatives/health workers, project co-ordinators and development workers

<sup>2</sup> Includes clinical therapists, nurses and other allied health professionals

<sup>3</sup> Includes HSE managers, Primary Care managers, Transformation Development Officers, Social Inclusion Manager

|   |  |      |            |
|---|--|------|------------|
|   | Paper 2; Chapter 5<br>Qualitative study employing interviews based on a participatory research approach  | n=3  |            |
| Patients/ members of marginalised groups interacting with or receiving services from PCTs | Paper 3; Chapter 6<br>Qualitative study employing focus groups and interviews based on a participatory research approach and using PLA methods | n=21 | n=21       |
| <b>Total</b>  |  |      | <b>629</b> |

In this study VanWynsberghe and Khan’s 2007 more encompassing definition of case study was employed. They define a case study as a ‘*transparadigmatic and transdisciplinary heuristic that involves the careful delineation of the phenomena for which evidence is being collected*’ [25]p. 80. They support Stake’s definition by clarifying that case study is neither a method nor a methodology. Similar to Yin, they suggest that instead, researchers employ various research methods, which act to build or uncover the case but because case study does not offer a prescriptive guide for how to proceed with the business of collecting, analysing and interpreting data, they do not consider case study as a research design [25]. Case study can be applied as an *approach* - this means that the case study is relevant regardless of one’s research paradigm and demands no particular disciplinary orientation. The seven common features of a prototypical case study as defined by VanWynsberghe and Khan [25] were applied to assess their fitness for this study. See Table 3.4.

**Table 3.4: VanWyssberghe and Kahn’s seven common features of a prototypical case study applied to this study [25]**

| <b>Feature</b>   | <b>Description applied to case study</b>   | <b>Applied to this study</b>   |
|--|--|--|
| <i>Feature 1: Small N.</i>                               | The case study calls for an intensive and in-depth focus on the specific unit of analysis and generally requires a much smaller sample size than survey research.  | Qualitative studies have small sample sizes supplemented by the larger survey data.  |
| <i>Feature 2: Contextual detail</i>                      | Case studies aim to give the reader a sense of ‘being there’ by providing a highly detailed, contextualized analysis of an ‘an instance in action’.  | Multiple perspectives of stakeholders enacting community participation on PCTs are described thus describing ‘an instance in action’.  |
| <i>Feature 3: Natural settings</i>                       | Case study researchers choose to systematically study situations where there is little control over behaviour, organisation, or events. Case study is uniquely suitable for research in complex settings because it advances the concept that complex settings cannot be reduced to single cause and effect relationships. | Complex policy implementation setting that interacted with the economic recession.   |
| <i>Feature 4: Boundedness</i>                            | Case studies provide a detailed description of a specific temporal and spatial boundary. Attending to place and time brings context to the structures and relationships that are of interest.  | Data were collected between the years 2011-2017. There were three spatial boundaries: the sites involved in the Joint Initiative, health care professionals working in primary health care settings and development of a local PCT in one location. Thus, multiple perspectives across relevant settings and stakeholders were examined. |
| <i>Feature 5: Working hypotheses and lessons learned</i> | Researchers can generate working hypotheses and learn new lessons based on what is uncovered or constructed during data collection and analysis in the   | Questions about enactment of community participation in primary health care were emerging as projects were underway. Community participation on PCTs is the unit of analysis studied and   |

| Feature                                 | Description applied to case study   | Applied to this study  |
|---|---|--|
|   | case study. The entity or phenomenon under study emerges throughout the course of the study, and it is this surfacing that can bring the study to a natural conclusion.   | emerged throughout the course of the study.  |
| <i>Feature 6: Multiple data sources</i> | Case study routinely uses multiple sources of data. This practice develops converging lines of inquiry, which facilitates triangulation and offers findings that are likely to be much more convincing and accurate.  | Multiple sources of data were used to triangulate and integrate findings about implementation of community participation on PCTs.  |
| <i>Feature 7: Extendibility</i>         | Case studies can enrich and potentially transform a reader's understanding of a phenomenon by extending the reader's experience. The case study researcher analyses complex social interactions to uncover or construct "inseparable" factors that are elements of the phenomena. | Complex integrated analysis happened where the data from three papers gave greater insight into the practice of community participation on PCTs thus uncovering invaluable facts for practice. |

There were also the strengths and criticisms of case study approach to consider which are outlined below.

### 3.4.1 Critique of a case study approach

Case studies have been criticised by some as lacking scientific rigour and reliability and that they do not address the issues of generalisability [29]. In doing a case study, the most difficult step is to define the "case" [28]. Inadequate definition can lead to two problems: (1) the findings might not be about the presumed case but about some other situation; and (2) if multiple cases have been conducted, they

might not be comparable in some fundamental way [28]. The volume of data, together with the time restrictions, can impact on the depth of analysis. Adequate time needs to be set aside for data analysis and interpretation of what are often highly complex datasets [29].

There are several ways to address these concerns, including: the use of theoretical sampling (i.e. drawing on a particular conceptual framework); respondent validation (i.e. participants checking emerging findings and the researcher's interpretation, and providing an opinion as to whether they feel these are accurate); and transparency throughout the research process [29]. Transparency can be achieved by describing in detail the steps involved in case selection, data collection, the reasons for the particular methods chosen, and the researcher's background and level of involvement; that is being explicit about how the researcher has influenced data collection and interpretation. Seeking potential alternative explanations, and being explicit about how interpretations and conclusions were reached, help readers to judge the trustworthiness of the case study report [29]. The potential pitfalls with case study research and how these were mitigated for in this study are outlined in Table 3.5.

In-depth reading was undertaken to understand the literature and the theoretical underpinning for the study. Focused data analysis pertaining to the research questions and clarity about the boundary of the case was established. Triangulation, respondent validation, and theoretical sampling all provided rigor to the research as

well as due attention to ethical issues arising. NPT was the theoretical framework underpinning the study.

**Table 3.5: Potential pitfalls and mitigating actions when undertaking case study research adapted from [29]**

| <b>Potential pitfall</b>  | <b>Mitigating action adapted in this study</b>  |
|---|---|
| Selecting/conceptualising the wrong case(s) resulting in lack of theoretical generalisations        | The PhD candidate developed in-depth knowledge of theoretical and empirical literature, justifying choices made across the three studies. This involved in-depth reading about NPT and relevant theories, as well as literature about sampling within a case study approach and identifying the unit of analysis. |
| Collecting large volumes of data that are not relevant to the case or too little to be of any value | Focused data analysis was undertaken in line with research questions pertaining to community participation on PCTs whilst being flexible and allowing other relevant data to be explored about primary health care policy and health disparities.   |
| Defining/bounding the case  | Defining the case focused on temporal and spatial boundaries and on related components (either by time and/or space). Clarity was developed about what was outside the scope of the case. Clear delineation was made about the unit of analysis and discussed in PhD meetings.                                    |
| Lack of rigour  | Triangulation, using different data sources, respondent validation of findings across the three papers, the use of theoretical sampling in the three papers, transparency throughout the research process all lent rigor to the development of the case.  |
| Ethical issues  | Ethical issues such as anonymity, confidentiality, participant welfare and informed consent of participants were assured throughout.  |
| Integration with theoretical framework  | Allowance was made for unexpected issues to emerge as suggested in the literature. NPT was the theoretical underpinning across the PhD but this was not forced, other theories were explored. There was active attention to data which fell outside the NPT constructs.   |

### 3.4.2 Research Design: Mixed Methods

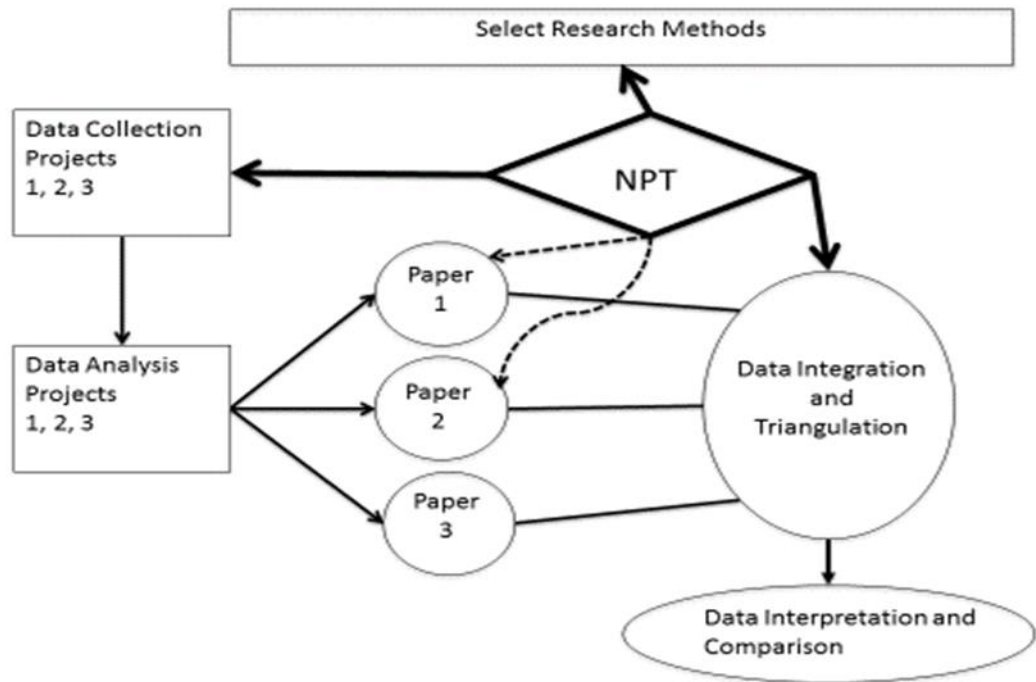
Within the case study approach, the research employed mixed methods. Mixed methods research is an approach compatible with pragmatic paradigm approach and combines both qualitative and quantitative forms of research. Increasingly, mixed methods are being used in primary health care research to contribute to a rich and comprehensive study [30, 31] and can add rigor and quality to study designs in primary care [32, 33].

Methodologists have emphasised the integration of qualitative and quantitative data as the centrepiece of mixed methods [34]. A mixed methods research design at its simplest level involves mixing both qualitative and quantitative methods of data collection and analysis in a single study [16]. A more elaborate definition specifies the nature of data collection (e.g., whether data are gathered concurrently or sequentially), the priority each form of data receives in the research (e.g., equal or unequal), and the place in the research process in which “mixing” of the data occurs such as in the data collection, analysis, or interpretation phase of inquiry. Combining all of these features, Creswell put forward the following definition: ‘*A mixed methods study involves the collection or analysis of both quantitative and/or qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research*’ [35]p. 165.

*Integration* is a term used in mixed methods research design. It is an intentional process by which the researcher brings quantitative and qualitative approaches together in a study [16]. It can refer to two points in the research process; the point in the process of research procedures at which the investigator mixes or integrates the quantitative and qualitative data collection, and the point at which the investigator mixes or integrates the data analysis [15]. The issue of integration illustrates the complexity of mixed methods research and the need to be explicit about the model of inquiry being used [31].

There are about forty mixed-methods research designs reported in the literature [15]. Creswell identified the six most often used designs, which include three concurrent and three sequential designs [35]. Sequential Explanatory, Sequential Exploratory, Sequential Transformative, Concurrent Triangulation, Concurrent Nested and Concurrent Transformative.

The sequential exploratory design [16] was the design most suitable for the integration of the mixed methods approach in this PhD study (also termed Multi-Level Sequential Mixed Design) [36]. This design combined data from across three research papers arising from the underpinning projects which were exploring different aspects of implementation of primary care policy in Ireland and underpinned by Normalisation Process Theory (see Figure 3.2).



**Figure 3.2: Sequential Exploratory Design approach applied to this study underpinned by NPT**

### **3.5 Theoretical Foundation: Normalisation Process Theory**

Theory is underused in implementation research [37]. The use of theory in implementation research offers three important potential advantages: a generalisable framework that can apply across differing settings and individuals, the opportunity for incremental accumulation of knowledge, and an explicit framework for analysis [37]. Furthermore, the use of theory enables the researcher to think creatively about the research, as it can improve understanding, explanation and prediction of implementation endeavours [38, 39]. The explicit application of theory can shorten the time needed to develop improvement interventions, optimise their design,

identify conditions necessary for success, and enhance learning to promote the transfer of learning from one project, one context, one challenge, to the next [40].

Understanding available theories is important, but should not be restricted by disciplinary perspectives, worldview, or area of application [37]. There is no one ideal universally accepted framework that will fit all purposes [37]. A number of theories were considered to be relevant to this area of implementation research; for example, Diffusions of innovation theory [41], COM-B (Capability, Opportunity, Motivation and Behaviour [42], Theoretical Domains Framework [43], Theories of Planned Behaviour [44], Reach, Efficacy, Adoption, Implementation and Maintenance Framework (RE-AIM)[45] and Consolidated Framework for Implementation Research (CFIR)[46] (see Appendix 5).

However, Normalisation Process Theory (NPT)[47] was the implementation theory used to explore the implementation of community participation on PCTs in this study. The rationale for using NPT was that it has the capacity to elucidate the details of small scale implementation work, but also to elucidate the ways in which macro, meso and micro levels of action and interaction shape that work [47]. NPT identifies four determinants of embedding complex interventions in practice (coherence or sense making, cognitive participation or engagement, enactment or collective action and appraisal or reflexive monitoring) and the relationships between these determinants [48]. NPT was also selected because one of its distinguishing features is that it is a theory of action, which is concerned with explaining what people do rather than their attitudes and beliefs. It also extends beyond the initial introduction

of innovation to investigate the processes by which innovation may become embedded and routinised in practice so that it becomes regarded as a normal and taken-for-granted way of working [49]. Furthermore, NPT provides a comprehensive theoretical framework for a ‘whole system’ analysis of the factors that promote or inhibit the routine embedding of complex interventions in health care practice and the work involved, by individuals and groups, to implement change in healthcare settings, (in this case community participation on PCTs)[47].

NPT was also deemed a good fit to this study as it met the suggested criteria for ‘good’ theory [50] (see Table 3.6). Furthermore, a review found that NPT is a beneficial heuristic device to explain and guide implementation processes and is recommended for use with multiple stakeholders to enable analysis of implementation from a range of perspectives [51].

**Table 3.6: Rationale for using NPT as a good theoretical fit for this PhD adapted from [50]**

| <b>Criteria for good theory</b>   | <b>NPT</b>  |
|---|---|
| Clarity of theoretical concepts: ‘Has the case been made for the independence of constructs from each other?’           | Four constructs of NPT can be used independently to explore various aspects of the intervention.  |
| Clarity of relationships between constructs: ‘Are the relationships between constructs clearly specified?’              | The relationships between the constructs have been specified and evidence for the relationships has been published.   |
| Measurability: ‘Is an explicit methodology for measuring the constructs given?’   | Each construct has four subcomponents which allows ‘measurability’ of the constructs.   |
| Testability: ‘Has the theory been specified in such a way that it can be tested?’                                       | The theory has been tested across a variety of primary care and health care settings.   |
| Being explanatory: ‘Has the theory been used to explain/account for a set of observations?’ Statistically or logically? | The theory explains how interventions and practices associated with the intervention become embedded or routine in practice. NPT is a beneficial heuristic device to explain and guide implementation processes [51]  |
| Generalisability: ‘Have generalisations been investigated across behaviours, populations and contexts?’                 | NPT has been increasingly applied to many different healthcare specialities and contexts, including mental health, allied health, acute healthcare and primary healthcare settings as an explanatory model to guide the development and implementation of complex interventions [55]. |
| Having an evidence base: ‘Is there empirical support for the propositions?’   | There is a variety of published papers accounting for evidence base of the theory [51].   |

NPT was employed in this study in the following ways:

In Paper 1 Chapter 4, NPT informed survey questions were designed to explore the respondent’s views of implementation of the Primary Care Strategy in Ireland. Data was revealed about progress of implementation of PCTs, the importance of community participation on PCTs as a resource for team working and the prevalence of community participation representatives on PCTs.

In Paper 2 Chapter 5, NPT informed the research questions for fieldwork and the data analysis about enactment of community participation in practice. In this paper data was generated about coherence about community participation on PCTs from across stakeholders' viewpoints, data about motivations to do this work and about champions who promote the work and support buy-in. Data was also generated about enactment of community participation on PCTs, resources required to enact the work and relationships to implement the work. Data also yielded information about the perceived impact of the work and appraisal of the work.

In Paper 3 Chapter 6, NPT informed the findings in the integrated analysis about enactment of community participation on PCTs via the views of marginalised people re their priorities for PCTs and relationships which support the work on the ground.

In Chapter 7, NPT informed integrated analysis of the study by analysing findings from across the three papers and this process is described in more detail below.

### **3.6 Approach to integrated data analysis using NPT**

Integration of qualitative and quantitative data at the interpretation and reporting level using the narrative approach was applied to data analysis in this PhD. Three approaches to integration through narrative in research reports are possible [52]. The weaving approach, integration through data transformation and the use of visual joint displays (see Table 3.7).

**Table 3.7: Integration of qualitative and quantitative data at the interpretation and reporting level [52, 53]**

| Approach to integration of data         | Description of analysis within the approach  |
|---|--|
| Integration through narrative           | <p><i>Weaving approach</i> involves writing both qualitative and quantitative findings together on a theme-by-theme or concept-by-concept basis.</p> <p>The <i>contiguous approach</i> involves the presentation of findings within a single report, but the qualitative and quantitative findings are reported in different sections.</p> <p>The <i>staged approach</i> occurs in multistage mixed methods studies when the results of each step are reported in stages as the data are analysed and published separately.</p>  |
| Integration through data transformation | <p>Two step approach: First, one type of data must be converted into the other type of data (i.e., qualitative into quantitative or quantitative into qualitative). Second, the transformed data are then integrated with the data that have not been transformed.</p> <p>The “fit” of data integration refers to coherence of the quantitative and qualitative findings and leads to three possible outcomes:</p> <ul style="list-style-type: none"> <li>• <i>Confirmation</i> occurs when the findings from both types of data confirm the results of the other.</li> <li>• <i>Expansion</i> occurs when the findings from the two sources of data diverge and expand insights of the phenomenon of interest.</li> <li>• <i>Discordance</i> occurs when the qualitative and quantitative findings are inconsistent, incongruous, contradict, conflict, or disagree with each other.</li> </ul> |
| Integration through joint displays      | <p>Data are brought together visually to draw out new insights. This provides a structure to discuss the integrated analysis.</p> <p>Provides a method and a cognitive framework for integration showing an intentional process with a clear rationale.</p>  |

Techniques have also been developed to support researchers to integrate data or findings in their mixed methods studies [34, 54]. They are the triangulation protocol, following a thread and use of a mixed methods matrix. In this study a triangulation protocol was used.

**Using a triangulation protocol** data are collected and analysed separately for each component to produce separate sets of findings. Researchers then attempt to combine these findings. The term in this context is used to describe corroboration between two sets of findings using different methods to gain a more complete picture [34]. The process of triangulating findings from different methods takes place at the interpretation stage of a study when data sets have been analysed separately [34]. A triangulation protocol [54] can be used to produce a coding matrix to display findings emerging from each component of a study on the same page. This also considers where there is agreement, partial agreement, silence, or dissonance between findings from different components [54]. Many mixed methods studies do not clearly identify where integration takes place [16].

In this study, the data *integration* followed a *contiguous approach*. The results are presented separately; for example, quantitative data analysis first in paper 1, (Chapter 4) then qualitative data analysis in papers 2 and 3 (Chapters 5 and 6). Integrated data *analysis* broadly followed a combination of the staged approach and integration through joint displays. A joint display (see Figure 3.2) provided a structure to discuss the integrated analysis and NPT constructs provided a cognitive

framework or a heuristic to cognitively ‘think through’ the findings showing an intentional process with a clear rationale underpinned by theory [53].

Overall findings were then brought together and a triangulation protocol [54], informed by NPT, was developed as a technique to integrate data in Chapter 7. Findings across the three papers were extracted and research questions were mapped onto the four constructs of NPT to test its suitability as a heuristic device which could reveal levers and barriers to implementation of policy (see Appendix 6). Questions were posed of the data about the strength of the construct across the three papers. Findings per construct and per paper were analysed asking: “how strong is the implementation of community participation on PCTs?” This was similar to the working definition for strong implementation as outlined in Paper 2, Chapter 5 (see Box 5.1). For this study, this method was also used as a benchmark to classify the implementation as strong, moderate or weak. The data was further analysed to explore levers and barriers to implementation of practice ‘on the ground’.

At every stage in the data analysis, attention was paid to quality and rigour. Further detail of these processes and quality and rigor applied in the research methodology across the three research projects and the PhD are outlined in Appendix 7.

### **3.7 Summary**

This chapter outlines the methodological approach to this PhD. A pragmatic approach resonated with the aims and objectives of this PhD and the key features of

a pragmatic approach fitted with the methodological approach in this PhD study. Data was drawn from quantitative and qualitative sources which offered an opportunity to answer a question about community participation on PCTs that could not be answered by one source alone. Combining and extending data analysis from across three projects allowed a greater understanding of real life policy implementation across a number of primary health care settings. Participatory Health Research (PHR) as a research paradigm also influenced the PhD candidate's thinking and methodological approach to this study.

Ethical approval was granted for the three projects and a key ethical consideration addressed was the use of three existing research projects to form the basis for this PhD study.

The case study approach employing mixed methods was the design of this PhD. The Sequential Exploratory Design was the design most suitable for integration of the data across three studies. Mixing methods from three separate projects and collating data from a variety of stakeholders lent strength to the design of the study.

Normalisation Process Theory (NPT) was the implementation theory underpinning the study and was used to integrate findings across three papers. The key rationale for using NPT was that it has the capacity to elucidate the details of small-scale implementation work and it is also a theory of action.

### 3.8 References

1. Kuhn, T.S., *The Structure of Scientific Revolutions*. Chicago (University of Chicago Press). 1962.
2. Guba, E.G. and Y.S. Lincoln, *Competing paradigms in qualitative research*. Handbook of qualitative research, 1994. **2**(163-194): p. 105.
3. Johnson, R.B. and A.J. Onwuegbuzie, *Mixed Methods Research: A Research Paradigm Whose Time Has Come*. Educational Researcher, 2004. **33**(7): p. 14-26.
4. DePoy, E., & Gitlin, L. N. *Introduction to research: Understanding and applying multiple strategies*. 2015: Elsevier Health Sciences.
5. Kuhn, T.S., *The structure of scientific revolutions*. 2012: University of Chicago press.
6. Blaikie, N., *Designing Social Research*. 2nd ed. 2009, Cambridge: Polity press
7. Blumer, H., *Symbolic Interactionism: Perspective and Method*. 1969, California: University of California Press
8. Denzin N.K., & Lincoln Y., *The SAGE Handbook of Qualitative Research*. 4th ed. 2011: SAGE.
9. Howe, K.R., *Against the quantitative-qualitative incompatibility thesis or dogmas die hard*. Educational Researcher, 1988. **17**(8): p. 10-16.
10. Cherryholmes, C.H., *Notes on pragmatism and scientific realism*. Educational Researcher, 1992. **21**(6): p. 13-17.
11. Murphy, J.P. and R. Rorty, *Pragmatism from Peirce to Davidson*. 1990.
12. Rorty, R., *Truth and freedom: A reply to Thomas McCarthy*. Critical Inquiry, 1990. **16**(3): p. 633-643.

13. Patton, M.Q., *Qualitative evaluation and research methods*. 1990, London: Sage.
14. Morgan, D.L., *Paradigms lost and pragmatism regained; methodological implications of combining qualitative and quantitative methods*. *Journal of Mixed Methods Research*, 2007. **1**(1): p. 48-76.
15. Tashakkori, A.T., C, *Handbook of mixed methods in social and behavioural research*. Vol. 2nd edition. 2010, Thousand Oaks, California: Sage.
16. Creswell, J.W., *Research design: qualitative, quantitative, and mixed methods approaches*. 2013, London: Sage.
17. Feilzer, M.Y., *Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm*. *Journal of Mixed Methods Research*, 2010. **4**(1): p. 6-16.
18. Mertens, D.M., *Mixed methods and the politics of human research: The transformative-emancipatory perspective*. *Handbook of Mixed Methods in Social and Behavioral Research*, 2003: p. 135-164.
19. International Collaboration for Participatory Health Research, *Position Paper 1: What is Participatory Health Research?* 2013, International Collaboration for Participatory Health Research: Berlin.
20. International Collaboration for Participatory Health Research, *Position Paper 2: Participatory Health Research: A Guide to Ethical Principles and Practice* 2013, International Collaboration for Participatory Health Research: Berlin.
21. Shippee, N.D., et al., *Patient and service user engagement in research: a systematic review and synthesized framework*. *Health Expectations*, 2013.

22. Salway, S., et al., *Researching health inequalities with Community Researchers: practical, methodological and ethical challenges of an 'inclusive' research approach*. Research Involvement and Engagement, 2015. **1**(1): p. 1-21.
23. Salsberg, J., Macaulay, A., and Parry, D., *A Guide to Researcher and Knowledge-User Collaboration in Health Research*. 2016; Available from: <http://www.cihr-irsc.gc.ca/e/44954.html>.
24. MacFarlane, A., Tierney, E. McEvoy, R., *A Framework for Implementation of Community Participation in Primary Health Care*. 2014, Univeristy of Limerick and Health Service Executive: Limerick.
25. VanWynsberghe, R. and S. Khan, *Redefining case study*. International Journal of Qualitative Methods, 2007. **6**(2): p. 80-94.
26. Yin, R.K., *Case study research: Design and methods 4th ed.* in *United States: Library of Congress Cataloguing-in-Publication Data*. 2009.
27. Stake, R.E., *The art of case study research*. 1995: Sage.
28. Yin, R.K., *Enhancing the quality of case studies in health services research*. Health Services Research, 1999. **34**(5 Pt 2): p. 1209.
29. Crowe, S., et al., *The case study approach*. BMC Medical Research Methodology, 2011. **11**(1): p. 100.
30. Borkan, J.M., *Mixed methods studies: a foundation for primary care research*. The Annals of Family Medicine, 2004. **2**(1): p. 4-6.
31. Creswell, J.W., M.D. Fetters, and N.V. Ivankova, *Designing A Mixed Methods Study In Primary Care*. The Annals of Family Medicine, 2004. **2**(1): p. 7-12.

32. DiCicco-Bloom, B. and B.F. Crabtree, *The qualitative research interview*. Medical Education, 2006. **40**(4): p. 314-321.
33. Greene, J.C. and V.J. Caracelli, *Defining and describing the paradigm issue in mixed-method evaluation*. New directions for evaluation, 1997. **1997**(74): p. 5-17.
34. O’Cathain, A., E. Murphy, and J. Nicholl, *Three techniques for integrating data in mixed methods studies*. BMJ, 2010. **341**: p. c4587.
35. Creswell, J., et al., *An Expanded Typology for Classifying Mixed Methods Research Info Design*. Handbook of Mixed Methods in Social and Behavioural Research, 2003.
36. Teddlie, C. and A. Tashakkori, *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. 2009: Sage Publications Inc.
37. Eccles, M.P., et al., *An implementation research agenda*. Implementation Science, 2009. **4**(1): p. 18.
38. Damschroder, L.J. and J.C. Lowery, *Evaluation of a large-scale weight management program using the consolidated framework for implementation research (CFIR)*. Implementation Science, 2013. **8**(1): p. 51.
39. Nilsen, P., *Making sense of implementation theories, models and frameworks*. Implementation Science, 2015. **10**(1): p. 53.
40. Davidoff, F., et al., *Demystifying theory and its use in improvement*. BMJ Qual Saf, 2015: p. bmjqs-2014-003627.
41. Rogers, E.M., *Diffusion of innovations*. 2010: Simon and Schuster.
42. Michie, S., L. Atkins, and R. West, *The behaviour change wheel: a guide to designing interventions*. Needed: physician leaders, 2014. **26**: p. 146.

43. Michie, S., et al., *Making psychological theory useful for implementing evidence based practice: a consensus approach*. *BMJ Quality & Safety*, 2005. **14**(1): p. 26-33.
44. Ajzen, I., *The theory of planned behavior*. *Organizational Behavior and Human Decision Processes*, 1991. **50**(2): p. 179-211.
45. Glasgow, R.E., T.M. Vogt, and S.M. Boles, *Evaluating the public health impact of health promotion interventions: the RE-AIM framework*. *Am J Public Health*, 1999. **89**(9): p. 1322-7.
46. Damschroder, L.J., et al., *Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science*. *Implementation Science*, 2009. **4**(1): p. 50.
47. May, C. and T. Finch, *Implementing, embedding, and integrating practices: An outline of Normalization Process Theory*. *Sociology*, 2009. **43**(3): p. 535-554.
48. Murray, E., et al., *Normalisation process theory: a framework for developing, evaluating and implementing complex interventions*. *BMC Medicine*, 2010. **8**(1): p. 63.
49. May, C., *Towards a general theory of implementation*. *Implementation Science*, 2013. **8**(1): p. 18.
50. Michie, S., et al., *ABC of behaviour change theories*. 2014: Silverback Publishing.
51. McEvoy, R., et al., *A qualitative systematic review of studies using the normalization process theory to research implementation processes*. *Implementation Science*, 2014. **9**(2).

52. Fetters, M.D., L.A. Curry, and J.W. Creswell, *Achieving Integration in Mixed Methods Designs—Principles and Practices*. Health Services Research, 2013. **48**(6 Pt 2): p. 2134-2156.
53. Guetterman, T.C., M.D. Fetters, and J.W. Creswell, *Integrating quantitative and qualitative results in health science mixed methods research through joint displays*. The Annals of Family Medicine, 2015. **13**(6): p. 554-561.
54. Farmer, T., et al., *Developing and implementing a triangulation protocol for qualitative health research*. Qualitative Health Research, 2006. **16**(3): p. 377-394.
55. Gillespie, B.M., et al., *Using normalisation process theory to evaluate the implementation of a complex intervention to embed the surgical safety checklist*. BMC Health Services Research, 2018. **18**(1): p. 170.

## **Chapter 4 Paper 1: Do primary care professionals agree about progress with implementation of Primary Care Teams: – Results from a cross sectional study<sup>4</sup>**

### **4.1 Abstract**

#### **Background:**

Primary care is the cornerstone of healthcare reform with policies across jurisdictions promoting interdisciplinary team working. The effective implementation of such health policies requires an understanding of the perspectives of all actors. However, there is a lack of research about health professionals' views of this process. This study compares Primary Healthcare Professionals' perceptions of the effectiveness of the Primary Care Strategy and Primary Care Team (PCT) implementation in Ireland.

#### **Methods:**

Design and Setting: e-survey of (1) General Practitioners (GPs) associated with a Graduate Medical School (N=100) and (2) Primary Care Professionals in 3 of 4 Health Service Executive (HSE) regions (N=2309). After piloting, snowball sampling was used to administer the survey. Descriptive analysis was carried out using SPSS. Ratings across groups were compared using non-parametric tests.

---

<sup>4</sup> Published in BMC Family Practice (2016) 17:163 DOI 10.1186/s12875-016-0541-9: Received: 1 December 2015 Accepted: 21 May 2016

**Results:**

There were 569 responses. Response rates varied across disciplines (71% for GPs, 22% for other Primary Healthcare Professionals (PCPs)). Respondents across all disciplines viewed interdisciplinary working as important. Respondents agreed on lack of progress of implementation of formal PCTs (median rating of 2, where 1 is no progress at all and 5 is complete implementation). GPs were more negative about the effectiveness of the Strategy to promote different disciplines to work together (median rating of 2 compared to 3 for clinical therapists and 3.5 for nurses,  $P=0.001$ ). Respondents identified resources and GP participation as most important for effective team working. Protected time for meetings and capacity to manage workload for meetings were rated as very important factors for effective team working by GPs, clinical therapists and nurses. A building for co-location of teams was rated as an important factor by nurses and clinical therapists though GPs rated it as less important. Payment to attend meetings and contractual arrangements were considered important factors by GPs but not by nurses or clinical therapists.

**Conclusion:**

PCPs and GPs agree there is limited PCT implementation. GPs are most negative about this implementation. There is some disagreement about which resources are most important for effective PCT working. These findings provide valuable data for clinicians and policy makers about implementation of interdisciplinary teams in primary care.

**Keywords:**

Policy Implementation, Health Care Surveys, Primary Health Care; Patient Care Team, General Practice, Interdisciplinary Teams, Health Policy

**4.2 Background**

The benefits of delivering primary care through interdisciplinary teams are well established [1-4]. Specific benefits have been reported for patients [9-12]; specifically patients with diabetes [5], hypertension [6], obesity [7] and depression [8]. Health Care Professionals have also noted advantages including improved professional satisfaction [11-13].

In some countries, such as the UK, interdisciplinary team work in primary care has been gradually normalised through organic processes over relatively long periods of time and is now routinely incorporated into healthcare system redesign. In other countries like the United States, the Patient-Centered Medical Home model is seen as a strategic opportunity to modernise primary care [14] and early demonstration projects show some promise. However, full implementation has been slow, falling behind other developed countries which have a commitment to primary care [14, 15]. Ireland is similar, where attempts are being made to implement ‘top down’ policies [16-20], aimed at encouraging the rapid development of interdisciplinary teamwork as a means of improving the quality and increasing the efficiency of primary care. These policy shifts are part of a response to the increasing demands placed on primary care by the major demographic and epidemiological transitions experienced by all of the advanced economies in recent years [21-23].

In Ireland, substantial reform of primary care was enshrined in policy in 2001 [20]. This Primary Care Strategy proposed an interdisciplinary approach to primary care, based around Primary Care Teams (PCTs) [24]. PCTs would comprise a wide range of health professionals, located in a single primary care centre [20,25]. Members of the PCT would include GPs, nurses/midwives, health care assistants, home helps, physiotherapists, occupational therapists, social workers and administrative personnel. A wider primary care network of other primary care professionals would support the team to provide services for the enrolled population of each primary care team. GPs would be encouraged to join together their existing lists of enrolled individuals and families with the PCTs.

The aims of the proposed developments were to provide: a greatly strengthened primary care system; an integrated, interdisciplinary, high-quality, team-based and user-friendly set of services for the public; enhanced capacity for primary care to complement the existing diagnosis and treatment focus in the areas of prevention, early intervention, rehabilitation and personal social services [20](page 13).

However, the implementation of this Strategy over the past decade has been described as ‘very challenging’ [26]. The limited evidence suggests that PCT working is not routine and it is still rare for GPs to work alongside other health professionals to provide an integrated primary care system [27]. Furthermore, the rates of adoption or adaption of actors involved has not been documented [28]. A key challenge for healthcare systems like Ireland’s is how best to deliver new interventions across the wide diversity of possible settings [29, 30, 22]. This poses important problems of *translational* research around the interactions of actors and

interests through which policies are implemented [31, 32] and the role of policy and practice contexts in shaping barriers and facilitators to implementation [33, 34].

Understanding the process of implementing policy in this particular area is further complicated by a diversity of interdisciplinary team types and multiple definitions in use across settings [16, 17, 35-38]. In this study we adopted the term ‘interdisciplinary’ team working as this is the term used in the Irish Primary Care Strategy [20].

Using this policy intervention in Ireland as a vehicle, we want to address this translational problem by examining the ways that different professional groups understand and interpret experiences of interdisciplinary team working. Because the existing evidence tends to focus on the perspectives of specific professional groups [39-45], this is an area where surprisingly little is known [46]. This is problematic given the fact that the opinions of a variety of professionals, should be taken into account during implementation processes [46]. Following recommendations to use theory in translational research [33], we drew on Normalisation Process Theory (NPT) [16] to inform this research. NPT concentrates on the notion of normalisation in health care settings; i.e., the point at which a new way of working becomes routine and taken-for-granted. It has four constructs: coherence, cognitive participation, collective action and reflexive monitoring, which allow exploration of *sense making, engagement, enactment and appraisal* of the practice or intervention in question. The unique feature of NPT compared with other implementation theories is that it has developed from comprehensive analyses of the implementation of complex interventions in healthcare settings representing a good ‘fit’ with our interest in the implementation of PCTs as a complex intervention in the health service in Ireland. A

recent review found that NPT is a beneficial heuristic device to explain and guide implementation processes and recommended that it be used with multiple stakeholders to enable analysis of implementation from a range of perspectives [47, 48].

The aim of this study was to better understand the perspectives on policy implementation of participating professional groups and to understand barriers to the implementation of interdisciplinary team working across disciplines.

## **4.3 Methods**

### **4.3.1 Study Context**

**The Health Service Executive (HSE)** is a national publicly funded organisation which provides health and social services in Ireland. It is divided into four regions to deliver those services at regional level. These regions are; HSE South, HSE West, HSE Dublin Mid-Leinster and HSE Dublin North East.

**General Practitioners (GPs):** There are about 2,500 GPs in Ireland. Most are in private practice but also have contracts with the HSE to provide services to those eligible for publicly funded primary care.

**Primary Care Teams in Ireland** were initially implemented in 2001 after the publication of the Primary Care Strategy. The intended composition is General Practice staff (including GPs, practice nurses, practice managers) and HSE staff

(including Public Health Nurses (PHN), Registered General Nurses (RGN), Physiotherapists, Occupational Therapists (OT), Social Workers, Speech and Language Therapists (SLT) and Administrative staff) with additional support from wider primary care networks, including pharmacists, dieticians, and other professionals.

### **4.3.2 Participants**

The participant groups in this study were staff in 100 general practices affiliated with a Graduate Entry Medical School in the Mid-West of Ireland. These practices represent the range of general practice types in the Irish context, the majority of which are based in city and/or town locations with GPs in full time employment and operating group practices [49].

Primary health care staff, employed by the HSE in three of Ireland's four HSE regions, were identified via the National Primary Care Office within the HSE. There are 2,309 whole time equivalent posts employed by the HSE in 380 PCTs in these regions, which serve a population of 3.5 million people <sup>a</sup>.

### **4.3.3 Survey design**

The survey instrument developed by the research team consisted of 32 questions and comprised closed and open-ended questions. The survey questions and content was designed following the principles for constructing web surveys [50] with reference to the Primary Care Strategy [20] and other pertinent literature on PCTs in Ireland [28,

53]. We reviewed the Primary Care Strategy and literature for key concepts and common findings about implementation of PCTs.

We also drew on our knowledge of Normalisation Process Theory [54] to formulate questions.

NPT informed questions were designed to explore the respondent's views of implementation of the Primary Care Strategy in Ireland. Specifically, Coherence was explored by Q1 and 2 about perceived importance of PCT working – does it *make sense?*; Cognitive Participation by Q6 and 7 which related to *engagement* in the PCT; Collective Action by Q10 and 11 which asked about resources needed to *enact* PCT working; and Reflexive Monitoring by Q3, 8 and 9 which explored *appraisals* of progress with implementation of the Primary Care Strategy overall and the implementation of participants' specific PCTs (see Survey in Appendix 8).

Respondents were also asked about the composition of their PCT and to give information on their own background (including demographic information, qualifications, number of years' experience). Following best practice [55, 56], the survey was piloted with relevant health professionals. This helped us to clarify goals and identify practical problems [55, 57]. Issues of flow, salience, and administrative ease were identified [57]. Self-reported completion time for those who finished the survey was on average 15 minutes, consistent with studies reported elsewhere [58].

The procedure for sending out the survey followed an adapted Dillman Tailored Design Method (TDM) to maximise response rates. The Dillman TDM consists of a series of precisely laid out steps [59, 60] for example sending an advance notice about the forthcoming study, and follow up reminder emails sent at regular intervals [60-63].

In addition, the questionnaire was delivered electronically, had a clear focus, was concise, and clearly designed, with a simple layout. A researcher was available to answer any queries [55, 56, 64].

The survey was piloted and conducted over a four month period in 2014.

#### **4.3.4 Sampling method**

The survey was sent by email to all GP Practices (n=100) affiliated with the Graduate Entry Medical School. No mailing list of all primary healthcare staff employed by the HSE in the three regions existed so a snowball sampling method was used: HSE managers and Primary Care Transformation Development Officers (n=39) in the three HSE regions were sent the survey by email and asked to distribute to all relevant staff.

#### **4.3.5 Statistical methods**

Descriptive statistics are presented as count (percentage) for categorical data and median (first quartile, third quartile) for rating scales and rankings. Cronbach's alpha was used as a measure of internal consistency of items related to progress of implementation and effectiveness of strategy and team working. Non-parametric tests were used to compare medians across groups. A 5% level of significance was used for all statistical tests. SPSS version 21 for Windows was used for the analysis.

### **4.4 Results**

#### **4.4.1 Response Rate**

There were 569 eligible responses including 71 GPs (response rate of 71%) and 498 other healthcare professionals (response rate at most 22% of HSE whole time equivalent posts). The distribution of occupations within the HSE regions and within the sample is given in Table 4.1.

**Table 4.1: Distribution of occupations in the HSE regions and the survey sample<sup>5</sup>**

| <b>Occupation</b>                                 | <b>% employed by HSE <sup>(i)</sup></b> | <b>% of valid responses<sup>(ii)</sup></b> |
|---|---|--|
| <b>Public health and general registered nurse</b> | <b>55.2%</b>                            | <b>17.7%</b>                               |
| <b>Physiotherapist</b>                            | <b>12.4%</b>                            | <b>17.7%</b>                               |
| <b>Occupational therapist</b>                     | <b>10.6%</b>                            | <b>21.6%</b>                               |
| <b>Speech and language therapist</b>              | <b>8.1%</b>                             | <b>13.8%</b>                               |
| <b>Social worker</b>                              | <b>2.0%</b>                             | <b>3.7%</b>                                |
| <b>Dietician</b>                                  | <b>1.7%</b>                             | <b>5.0%</b>                                |
| <b>Psychologists/Counsellors</b>                  | <b>1.6%</b>                             | <b>3.4%</b>                                |
| <b>Other</b>                                      | <b>8.4%</b>                             | <b>17.1%</b>                               |

Respondents from the HSE in the main comprised OTs, Physiotherapists and SLTs (hereafter and for the purposes of this paper grouped together and called clinical therapists). While most occupations within the HSE were adequately represented in the sample, nurses were under represented. Of the 71 GPs who responded, 34% were in rural practices, 41% were in mixed urban/rural practices and 24% were in urban practices, largely representative of all GP practices in Ireland. Response rates across the three regions were broadly similar (Table 4.2).

<sup>5(i)</sup> Whole time equivalent posts <sup>(ii)</sup>Survey respondents who gave their occupation excluding general practitioners

#### **4.4.2 Demographics**

Of those who provided valid demographic information (n=427), respondents were predominantly female (82%) and the majority (72%) were aged less than 50 years.

The majority of respondents (53%) were 15 years or more post qualification.

Of the 71 GPs, the majority (62%) were male; aged 50 years or more (57%) and were 15 years or more post qualification (67%), representative of the GP profile in Ireland [49].

**Table 4.2: Demographics of respondents (n=569)**

| <b>Characteristic</b>                       | <b>n</b> | <b>% of total responses</b> | <b>% of valid responses<sup>(iii)</sup> 6</b> |
|---|----------|-----------------------------|---|
| <b>Age group</b>                            |          |                             |   |
| ≤ 35  | 106      | 18.6                        | 25.1  |
| 36-49                                       | 197      | 34.6                        | 46.7  |
| ≥50   | 119      | 20.9                        | 28.2  |
| Not given                                   | 147      | 25.8                        |   |
| <b>Gender</b>                               |          |                             |   |
| Female                                      | 344      | 60.5                        | 81.5  |
| Male  | 78       | 13.7                        | 18.5  |
| Not given                                   | 147      | 25.8                        |   |
| <b>Occupation</b>                           |          |                             |   |
| Occupational therapist                      | 77       | 13.5                        | 18.0  |
| General practitioner                        | 71       | 12.5                        | 16.6  |
| Physiotherapist                             | 63       | 11.1                        | 14.8  |
| Public health/registered general nurse      | 63       | 11.1                        | 14.8  |
| Speech and language therapist               | 49       | 8.6                         | 11.5  |
| Manager                                     | 25       | 4.4                         | 5.9   |
| Dietician                                   | 18       | 3.2                         | 4.2   |
| Social Worker                               | 13       | 2.3                         | 3.0   |
| Psychologist /Counsellor                    | 12       | 2.1                         | 2.8   |
| Other occupations <sup>(iv)</sup>           | 36       | 6.3                         | 8.4   |
| No occupation given                         | 142      | 25.0                        |   |
| <b>Years since qualification</b>            |          |                             |   |
| 1-5   | 32       | 5.6                         | 7.7   |
| 5-10  | 76       | 13.4                        | 18.3  |
| 10-15                                       | 89       | 15.6                        | 21.4  |
| 15+   | 219      | 38.5                        | 52.6  |
| Not given                                   | 153      | 26.9                        |   |
| <b>HSE Region</b>                           |          |                             |   |
| HSE West                                    | 174      | 30.6                        | 42.2  |
| HSE Dublin Mid-Leinster                     | 143      | 25.1                        | 34.7  |
| HSE South                                   | 95       | 16.7                        | 23.1  |
| Not given                                   | 157      | 27.6                        |   |
| <b>Member of a formal primary care team</b> |          |                             |   |

<sup>6(iii)</sup> % of responses excluding not given

<sup>(iv)</sup> home help, community pharmacist, community worker, dentist, primary care facilitator, community doctor, general practice administration staff, general practice nurse, community welfare officer, area medical officer

| Characteristic           | n   | % of total responses | % of valid responses <sup>(iii)</sup> 6 |
|--------------------------|-----|----------------------|---|
| Yes                      | 388 | 68.2                 | 78.1                                    |
| No                       | 109 | 19.2                 | 21.9                                    |
| Not applicable/not given | 72  | 12.6                 |   |

#### 4.4.3 Composition of Primary Care Teams

78% of respondents reported that they were a member of a formal PCT. Of those who were a member of a team (n=388), 34% were a member of two or more teams and 81% had been a member of a team for five years or less.

72% reported that they frequently or very frequently attended PCT meetings. Only 7% reported that they never attended meetings. When asked to name who was on their PCT, the most frequently cited profession was PHN (77%), followed by OT (75%), Physiotherapist (75%), GP (57%), SLT (52%) and RGN (51%). Pharmacists (3%), Community Welfare Officers (6.7%) and Social Workers (9.5%) were the least frequently cited professions.

**Table 4.3: Characteristics of primary care teams for named members of formal PCTs (n=388)<sup>(v)7</sup>**

| <b>Characteristic</b>                               | <b>n (%)</b> |
|---|--------------|
| <b>How many teams are you a member of?</b>          |              |
| <b>One</b>  | 249 (65.7)   |
| <b>Two</b>  | 84 (22.2)    |
| <b>Three or more</b>                                | 46 (12.1)    |
| <b>How long have you been a member of the team?</b> |              |
| <b>0-1 year</b>                                     | 70 (19.2)    |
| <b>1-5 years</b>                                    | 225 (61.8)   |
| <b>5 or more years</b>                              | 69 (19.0)    |
| <b>How often do you attend meetings?</b>            |              |
| <b>Very frequently</b>                              | 172 (44.8)   |
| <b>Frequently</b>                                   | 105 (27.3)   |
| <b>Infrequently/Rarely/Never</b>                    | 107 (27.9)   |
| <b>Who is on your team?</b>                         |              |
| <b>Public health nurse</b>                          | 300 (77.3)   |
| <b>Occupational therapist</b>                       | 293 (75.5)   |
| <b>Physiotherapist</b>                              | 291 (75.0)   |
| <b>General practitioner</b>                         | 221 (57.0)   |
| <b>Speech and language therapist</b>                | 202 (52.1)   |
| <b>Registered general nurse</b>                     | 199 (51.3)   |
| <b>Home help co-ordinator</b>                       | 176 (45.4)   |
| <b>Dietician</b>                                    | 136 (35.1)   |
| <b>Administrator</b>                                | 128 (33.0)   |
| <b>Clinical psychologist</b>                        | 83 (21.4)    |
| <b>Counsellor</b>                                   | 46 (11.9)    |
| <b>Community representative</b>                     | 40 (10.3)    |
| <b>Social worker</b>                                | 37 (9.5)     |
| <b>Community welfare officer</b>                    | 26 (6.7)     |
| <b>Pharmacist</b>                                   | 10 (2.6)     |
| <b>Other<sup>(vi)</sup></b>                         | 28 (7.2)     |

<sup>7</sup> <sup>(v)</sup>Missing responses for some characteristics - % of valid responses reported

<sup>(vi)</sup> Community Psychiatry/Mental Health, Community Worker, Drugs and Alcohol Counsellor, Chiropodist, Elder Day Care Managers, Care Provider Agency, Community Hospital Representative, Hospital Palliative Nurse, Diabetic Nurse, Smoking Cessation Officer, Specialist Liaison Nurse

#### **4.4.4 Perceptions of PCT working and progress with PCT implementation in Ireland**

Respondents rated *the importance of interdisciplinary working* as 5, on average; on a 5 point scale where 1 is not at all important and 5 is extremely important (Table 4.4). Comparing the three largest groups (clinical therapists, GPs and nurses), while both nurses and clinical therapists rated the importance of interdisciplinary working higher on average compared to GPs (median of 5 compared to 4 for GPs,  $P < 0.001$ ), all three groups rated it as important.

The following four items on the questionnaire ( Q2, Q3, Q8 Q9 ) related to progress with implementation and effectiveness of the Primary Care Strategy and team working. The value of Cronbach's alpha was 0.7 for these items indicating acceptable internal consistency.

**Table 4.4: Health professional views of policy implementation; Median rating (1<sup>st</sup> quartile, 3<sup>rd</sup> quartile) for all respondents (n=569) and by occupation**

| <b>Occupation</b>                              | <b>Importance of multidisciplinary work (1=not at all important, 5=extremely important)</b> | <b>General progress of implementation (1=no progress at all, 5=complete implementation )</b> | <b>Effectiveness of HSE strategy (1=not at all effective, 5=extremely effective)</b> |
|--|---|--|--|
| Clinical Therapist (n=189)                     | 5 (5, 5)  | 3 (2, 3)   | 3 (2, 4)   |
| GP (n=71)                                      | 4 (3, 5)  | 2 (2, 2)   | 2 (1, 3)   |
| Nurse (n=63)                                   | 5 (5, 5)  | 2 (2, 3)   | 3.5 (3, 4)   |
| Manager (n=25)                                 | 5 (5, 5)  | 3 (2, 3)   | 3 (3, 4)   |
| Social worker/ Psychologist/ Counsellor (n=25) | 5 (4, 5)  | 2 (2, 3)   | 3 (2, 4)   |
| Dietician (n=18)                               | 5 (5, 5)  | 3 (2, 3)   | 3 (2, 4)   |
| Other occupations (n=36)                       | 5 (4, 5)  | 2 (2, 3)   | 3 (2, 4)   |
| No occupation given (n=142)                    | 5 (4, 5)  | 3 (2, 3)   | 3 (3, 4)   |
| All respondents (n=569)                        | 5 (4, 5)  | 2 (2, 3)   | 3 (2, 4)   |

Respondents rated the *general progress of implementation* of formal PCTs as 2, on average, on a five-point scale where 1 is no progress at all and 5 is complete implementation (Table 4.4). 32 respondents (6%) reported no progress at all and 4 (1%) reported complete implementation. Comparing the three largest groups, clinical therapists tended to have more positive views on progress (median of 3 compared to 2 for both GPs and nurses,  $P < 0.001$ ).

Views on the *effectiveness of the Primary Care Strategy* to promote different disciplines to work together were slightly more positive with a rating across all respondents of 3, on average; on a five-point scale where 1 is not at all effective and 5 is extremely effective. Again, GPs were more negative about the effectiveness of the Primary Care Strategy to promote interdisciplinary working with an average rating of 2 compared to 3 for clinical therapists and 3.5 for nurses ( $P=0.001$ ).

Views on the progress of *implementation of the primary care teams which respondents were members of (n=388)* were also slightly more positive than the views on general progress with an average rating of 3 on a 5-point scale where 1 is no progress at all and 5 is complete implementation. GPs tended to have more negative views about the teams which they were members of than all other respondents (median of 2 compared to 3 for all others) though this difference was not significant ( $P=0.08$ ).

The *effectiveness of the team working together* was rated by team members as 3 on average on a five-point scale where 1 is not at all effectively and 5 is very effectively. Comparing the three largest groups, both nurses and GPs had more negative views on the effectiveness of the team working together compared to clinical therapists (median of 2 compared to 3,  $P=0.01$ ).

**Table 4.5: Views on the progress of implementation of primary care teams by members of those teams, Median rating (1<sup>st</sup> quartile, 3<sup>rd</sup> quartile) for all named members of formal PCTs (n=388) and by occupation**

| <b>Occupation</b>                                    | <b>Progress of implementation of PCTs you are a part of (1=no progress at all, 5=complete implementation )</b> | <b>Effectiveness of PCT members working together as a formal team (1=not at all effectively, 5=very effectively)</b> |
|--|--|--|
| Clinical Therapist (n=148)                           | 3 (2, 4)   | 3 (2, 4)   |
| GP (n=61)  | 2 (1.5, 3)   | 2 (2, 3)   |
| Nurse (n=51)   | 3 (2, 3)   | 2 (2, 3)   |
| Social worker/<br>Psychologist/<br>Counsellor (n=16) | 3 (2.5, 4)   | 3 (2, 4)   |
| Manager (n=7)  | 3 (2, 4)   | 2 (2, 3.5)   |
| Dietician (n=12)                                     | 3 (2, 3.5)   | 2 (2, 3)   |
| Other occupations (n=21)                             | 3 (2, 4)   | 3 (3, 4)   |
| No occupation given (n=72)                           | 3 (2, 4)   | 3 (2, 4)   |
| All team members (n=388)                             | 3 (2, 4)   | 3 (2, 4)   |

#### **4.4.5 Requirements for effective PCT working to support its implementation**

Respondents ranked resources and GP participation as most important factors to promote effective team working with community participation and waiting list systems ranked as least important factors. These findings were consistent across the three largest groups.

**Table 4.6: Rank order of factors required for effective PCT working - views across three largest disciplines**

| <b>Occupation</b>          | <b>Most important factors<sup>(vii)</sup></b>                   | <b>Less important factors<sup>(viii)8</sup></b>  |
|----------------------------|---|--|
| Clinical Therapist (n=189) | Resources<br>GP participation<br>Communication<br>Leadership    | Time of meetings<br>Clarity re roles<br>Skills, knowledge and training<br>Community participation<br>Waiting list system |
| GP (n=71)                  | Resources<br>Time of meetings<br>GP participation<br>Leadership | Clarity re roles<br>Skills, knowledge and training<br>Communication<br>Community participation<br>Waiting list system    |
| Nurse (n=63)               | GP participation<br>Resources<br>Time of meetings<br>Leadership | Clarity re roles<br>Skills, knowledge and training<br>Communication<br>Community participation<br>Waiting list system    |

When asked about *the importance of resources for PCT meetings*, protected time for meetings and capacity to manage workload associated with meetings were rated as very important by the three largest groups. A building for co-location of teams was rated as important by nurses and clinical therapists though GPs rated it as less

<sup>8</sup> (vii) Median ranking of importance 1-4 on a 9-point scale where 1 is most important and 9 is least important

(viii) Median ranking of importance of 5 or above on a 9-point scale where 1 is most important and 9 is least important

important. Payment to attend meetings and contractual arrangements were considered important resources by GPs but not by nurses or clinical therapists.

**Table 4.7: Ranking of required resources for effective team working by three largest groups<sup>9</sup>**

| <b>Occupation</b>          | <b>Most important resources<sup>(ix)</sup></b>  | <b>Less important resources<sup>(x)</sup></b>              |
|----------------------------|---|--|
| Clinical Therapist (n=189) | Capacity to manage workload associated with meetings<br>Protected time for meetings<br>PCT building to have co-located team members               | Payment for attending meetings<br>Contractual arrangements |
| GP (n=71)                  | Capacity to manage workload associated with meetings<br>Protected time for meetings<br>Payment for attending meetings<br>Contractual arrangements | PCT building to have co-located team members               |
| Nurse (n=63)               | Capacity to manage workload associated with meetings<br>Protected time for meetings<br>PCT building to have co-located team members               | Payment for attending meetings<br>Contractual arrangements |

<sup>9</sup>(ix)Median rating of importance above 3 on a five point scale where 1 is not at all important and 5 is very important

(x) Median rating of importance of 3 or below on a five point scale where 1 is not at all important and 5 is very important

## **4.5 Discussion**

### **4.5.1 Summary**

The majority of respondents in this study reported little progress or no progress at all with implementation of the Primary Care Strategy in Ireland in general. Clinical therapists were more positive about PCT implementation than nurses or GPs. GPs were most negative about implementation of the specific PCTs that they have experience of.

Resources and GP participation were considered important factors to promote team working across all disciplines. Payment for meetings and contractual arrangements were considered more important resources for effective team working for GPs than for other professions. Working from a co-located PCT building was considered less important by GPs than other professions.

### **4.5.2 Strengths and limitations**

The majority of the sample were named members of a formal PCT, providing us with the views of experienced professionals working across established interdisciplinary teams in Ireland. Over a quarter of these, however, did not frequently attend meetings giving us an insight on implementation from those with different levels of engagement as recommended by Carlford and Festin [46].

There are many hurdles to accessing the many different actors involved in the policy process [65]. The variation in response rate from 71% for GPs to 22% for HSE staff should be viewed in the context of weaknesses in health information systems in the HSE – there is no mailing list of all HSE staff in the three regions. We were dependent on HSE managers and Transformation Development Officers to distribute the survey to relevant staff but had no way of knowing how many of these actually received it. While public health nurses (PHNs) and Registered General Nurses (RGNs) make up over half of the whole time equivalent posts in the HSE, only 18% of the sample who gave an occupation were nurses. This underrepresentation may be due to the setting in which PHNs work in Ireland with limited access to email. We acknowledge this limitation and recommend that in future surveys, strategies to target a higher response rate across nursing professions be identified. Where a mailing list existed (GPs), responses were received from 71 of the 100 practices, despite GPs being recognised as a professional group from which it is difficult to obtain high response rates [64, 66, 67].

#### **4.5.3 Comparison with existing literature**

It is known that health policy implementation must be informed by an understanding of the actors through which policies are developed and implemented [22, 31-33, 22].

This study focused on the views of health professionals as key actors in the policy implementation process. Findings show that there is disagreement in Irish health professionals' views about how effective a top down policy is to promote interdisciplinary working. GPs were more negative about the implementation of the

Primary Care Strategy in relation to their specific PCTs than nurses and clinical therapists. The findings resonate with previous research in Ireland with single professional groups [39, 68, 69] but, for the first time, show how professionals' views compare with each other.

As reported elsewhere [28, 37, 43, 70] resources were considered important for PCTs to work effectively as was GP participation [43, 53, 69]. Consistent with other research [4, 28, 37, 45, 70] protected time for meetings and capacity to manage workload associated with meetings was rated as very important by nurses, clinical therapists and GPs.

However, our findings show variation between the groups about the resources important for effective PCT implementation. Similar to previous research [71], payment to attend meetings and contractual arrangements were only rated important by GPs. This is likely to be explained by the self-employed nature of GPs' fee-for-service contractual arrangements compared to the salaried positions of HSE staff in Ireland. This reflects findings in New Zealand where, in salaried practices, doctors and nurses alike were employees and were particularly supportive of team working [37].

Interestingly, a PCT co-located building was rated as important by clinical therapists and nurses but not by GPs despite the evidence that co-location of practitioners may improve access to services and equipment that aid chronic disease management [23]. These findings are likely to be explained by the nature of the environment in which

GPs work in Ireland – the majority work in privately owned facilities and may have discomfort about working in buildings owned by the HSE. We are currently exploring further in a qualitative study how these differential views impact on GP engagement and the nature of collaborations and dissidence between GPs and other professions [12, 72, 73].

Interestingly, there was agreement across GPs, clinical therapists and nurses that community participation and waiting list systems were the least important factors for effective PCT working. The former is strongly advocated in international and national policy but only 10% reported that there was community participation on their PCT. The latter remains a significant challenge in the Irish healthcare service and so it is surprising that it would be considered least important by all disciplines.

#### **4.5.4 Implications for research and/or practice**

In this study NPT was helpful to generate questions to explore views about implementation of a top-down policy with regard to patterns of shared and differential experiences across team members as well as the resources and factors important for implementation. We are limited in our ability to analyse findings *in-depth* using NPT given the nature of survey data. However, we can identify questions for further research to generate evidence about the extent to which top-down initiatives are effective in general as mechanisms of translation. It would be valuable to explore how the constructs of NPT may impact one another in the implementation process. For example:

Does the 'work' involved in enacting and embedding PCT work (collective action) make more sense (coherence) to different types of professionals because of their relationship with the HSE and, consequently, directives for interdisciplinary working (cognitive participation)? Does PCT working simply sit better with HSE employees compared with GPs because of how they understand their 'job'?

We found differences in opinion about co-location between GPs and other health professionals and it would be interesting to explore if co-location supports the flow of communication between professional groups (greater collective action), and why this may not be the same for GPs.

Does frequent involvement in PCT meetings (cognitive participation) mean that interdisciplinary working makes more sense (coherence) and thus, fuel efforts to reconfigure practices to overcome any barriers to interdisciplinary working (reflexive monitoring)?

We are currently exploring these issues in the aforementioned follow up qualitative study using NPT as our guiding framework.

#### **4.6 Conclusion**

Primary Health Care Professionals in Ireland agree about the lack of progress with the implementation of PCTs. GPs are more negative than their colleagues from

nursing and clinical therapy backgrounds. GPs also have different views about which resources are required to promote team working and these reflect health system funding and organisational factors. Attention to such differential views on PCT working is required to enhance the development and function of PCTs in Ireland.

## **4.7 Declarations**

### **4.7.1 List of Abbreviations**

The Health Service Executive (HSE)

General Practitioners (GPs)

Primary Care Teams (PCTs)

Transformation Development Officers (TDOs)

Public Health Nurses (PHN)

Registered General Nurses (RGN)

### **4.7.2 Funding**

This project was funded by the Health Research Board Ireland. The funding body had no role in the design of the study, data collection, analysis or interpretation or in writing this manuscript.

### **4.7.3 Ethical approval**

This study received ethical approval from the Irish College of General Practitioners Ireland (ICGP).

The online survey was sent via email to respondents and response was voluntary and anonymous. Consent to participate was indicated by completion of the online survey. This mechanism of consent was approved by ICGP.

#### **4.7.4 Consent to publish**

Not applicable

#### **4.7.5 Competing interests**

The authors declare that they have no competing interests

#### **4.7.6 Authors Contributions**

ET and AMacF led on the design and administration of the survey and contributed to data analysis.

MOS, WC, CM, NK, LK contributed to the design of the survey and to data analysis.

AH led on statistical analysis with LH.

All authors contributed to the write up and have approved the final manuscript

#### **4.7.7 Availability of data and materials**

Data will not be made available at this time as analysis of data set is ongoing by the research team.

#### **4.8 Acknowledgements**

Not applicable

#### **4.9 Authors' information**

**ET, MOS, LH, AH and AMacF are all members of a Primary Health Care Research group at the University of Limerick.** This is an interdisciplinary primary healthcare group at the Graduate Entry Medical School with members from general practice, speech and language therapy, physiotherapy, sociology, psychology and biostatistics. The group are leaders in Public and Patient Involvement research and conduct participatory health research with socially excluded communities as well as research about primary health care systems and reform.

#### **4.10 Endnotes<sup>a</sup>**

HSE. Staffing in Primary Care Teams in Ireland; Summary report: HSE 2014.

Received via personal email correspondance

#### **4.11 References**

1. Long S. Primary health care team workshop: team members' perspectives. *Journal of Advanced Nursing*. 1996;23(5):935-41. doi:10.1046/j.1365-2648.1996.10911.x.
2. Shaw A, de Lusignan S, Rowlands G. Do primary care professionals work as a team: a qualitative study. *J Interprof Care*. 2005;19(4):396-405. doi:10.1080/13561820500053454.
3. Van Weel C. Teamwork. *The Lancet*. 1994;344(8932):1276-9.
4. Kennedy N, Armstrong C, Woodward O, Cullen W. Primary care team working in Ireland: a qualitative exploration of team members' experiences in

a new primary care service. *Health Soc Care Comm.* 2015;23:362-70.

doi:doi: 10.1111/hsc.12150.

5. Renders CM, Valk GD, Griffin S, Wagner EH, Eijk JT, Assendelft WJ. Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings. *Cochrane Database Syst Rev.* 2001(1):Cd001481. doi:10.1002/14651858.cd001481.
6. Adorian D, Silverberg DS, Tomer D, Wamosher Z. Group discussions with the health care team--a method of improving care of hypertension in general practice. *Journal of Human Hypertension.* 1990;4(3):265-8.
7. Flodgren G, Parmelli E, Doumit G, Gattellari M, O'Brien MA, Grimshaw J et al. Local opinion leaders: effects on professional practice and health care outcomes. *Cochrane Database Syst Rev.* 2011(8):Cd000125. doi:10.1002/14651858.CD000125.pub4.
8. Bower P, Gilbody S, Richards D, Fletcher J, Sutton A. Collaborative care for depression in primary care. Making sense of a complex intervention: systematic review and meta-regression. *British Journal of Psychiatry.* 2006;189:484-93. doi:10.1192/bjp.bp.106.023655.
9. Sommers LS, Marton KI, Barbaccia JC, Randolph J. Physician, nurse, and social worker collaboration in primary care for chronically ill seniors. *Archives of Internal Medicine.* 2000;160(12):1825-33.
10. Jackson G, Gater R, Goldberg D, Tantam D, Loftus L, Taylor H. A new community mental health team based in primary care. A description of the service and its effect on service use in the first year. *The British Journal of Psychiatry.* 1993;162(3):375-84.

11. Mickan S, Hoffman SJ, Nasmith L. Collaborative practice in a global health context: Common themes from developed and developing countries. *Journal of Interprofessional Care*. 2010;24(5):492-502. doi: 10.3109/13561821003676325.
12. Schadewaldt V, McInnes E, Hiller J, Gardner A. Views and experiences of nurse practitioners and medical practitioners with collaborative practice in primary health care - an integrative review. *BMC Family Practice*. 2013;14(1):132.
13. Sinsky CA, Willard-Grace R, Schutzbank AM, Sinsky TA, Margolius D, Bodenheimer T. In Search of Joy in Practice: A Report of 23 High-Functioning Primary Care Practices. *The Annals of Family Medicine*. 2013;11(3):272-8. doi:10.1370/afm.1531.
14. Phillips RL, Bazemore AW. Primary Care And Why It Matters For U.S. Health System Reform. *Health Affairs*. 2010;29(5):806-10. doi:10.1377/hlthaff.2010.0020.
15. Starfield B. IS us health really the best in the world? *JAMA*. 2000;284(4):483-5. doi:10.1001/JAMA 284.4.483.
16. Department of Health. National Primary Health Care Strategic Framework Sydney, Australia: Department of Health, Government of Australia 2013.
17. Department of Health. Transforming Primary Care London: Department of Health, Government of the United Kingdom 2014.
18. Health Council of Canada. Teams in Action: Primary Care Teams for Canadians Toronto: Health Council of Canada; 2009.

19. Van Weel C, Schers H, Timmermans A. Health care in the Netherlands. *The Journal of the American Board of Family Medicine*. 2012;25(Suppl 1):S12-S7.
20. Department of Health and Children. *Primary care: A New Direction*. Dublin: Department of Health and Children 2001.
21. Kringos D, Boerma W, Bourgueil Y, Cartier T, Dedeu T, Hasvold T et al. The strength of primary care in Europe: an international comparative study. *BMJ*, 2013;63(616):e742-e50. doi:10.3399/bjgp13X674422.
22. Peters D, H., Tran, Nhan, T., Adam, Taghreed. *Implementation research in health; a practical guide*. Alliance for Health Policy and Systems Research, Geneva. 2013.
23. Rumball-Smith J, Wodchis WP, Koné A, Kenealy T, Barnsley J, Ashton T. Under the same roof: co-location of practitioners within primary care is associated with specialized chronic care management. *BMC Family Practice*. 2014;15(1):149. doi:10.1186/1471-2296-15-149.
24. Curry J. *Irish social services*. Institute of Public Administration; 2003.
25. Joint Committee on Health and Children. *Report on Primary Medical Care in the Community Dublin Houses of the Oireachtas* Joint Committee on Health and Children 2010.
26. Houses of the Oireachtas. *GPs and the Irish Primary Care System: Towards Universal Primary Care?* Dublin: Houses of the Oireachtas 2014.
27. Layte R. *Projecting the impact of demographic change on the demand for and delivery of healthcare in Ireland*. ESRI; 2009.

28. O'Sullivan M, W Cullen, MacFarlane A. Primary Care Teams in Ireland: A qualitative mapping review of Irish grey and published literature. *Irish Journal of Medical Science* 2014. doi: 10.1007/s11845-014-1128-x.
29. Brock D, Abu-Rish E, Chiu C-R, Hammer D, Wilson S, Vorvick L et al. Interprofessional education in team communication: working together to improve patient safety. *BMJ Quality & Safety*. 2013;22(5):414-23. doi:10.1136/bmjqs-2012-000952.
30. Oni T, McGrath N, BeLue R, Roderick P, Colagiuri S, May CR et al. Chronic diseases and multi-morbidity - a conceptual modification to the WHO ICCM model for countries in health transition. *BMC Public Health*. 2014;14(575):1-13.
31. Gilson L. Health policy and systems research A Methodology Reader. 2012.
32. Lipsky M. *Street-Level Bureaucracy*, 30th Ann. Ed.: Dilemmas of the Individual in Public Service. Russell Sage Foundation; 2010.
33. Eccles M, Armstrong D, Baker R, Cleary K, Davies H, Davies S et al. An implementation research agenda. *Implementation Science*. 2009;4(1):18. doi:10.1186/1748-5908-4-18.
34. Grembowski D, Schaefer J, Johnson KE, Fischer H, Moore SL, Tai-Seale M et al. A Conceptual Model of the Role of Complexity in the Care of Patients With Multiple Chronic Conditions. *Med Care*. 2014;52:S7-S14.
35. Mathieu J, Maynard MT, Rapp T, Gilson L. Team effectiveness 1997-2007: A review of recent advancements and a glimpse into the future. *Journal of Management*. 2008;34(3):410-76. doi:10.1177/0149206308316061.

36. McCallin A. Interdisciplinary practice ± a matter of teamwork: an integrated literature review. *Journal of Clinical Nursing*. 2001;10:419-28.  
doi:<http://dx.doi.org/10.1046/j.1365-2702.2001.00495.x> PMID:11822488.
37. Pullon S ME, Dew K. Primary health care in New Zealand: the impact of organisational factors on teamwork. *Br J Gen Pract* 2009;59(560):191-7.  
doi:<http://dx.doi.org/10.3399/bjgp09X395003> PMID:19275835  
PMCID:PMC2648917.
38. Health Council of Canada. *Teams in Action: Primary Health Care Teams for Canadians*. Toronto: Health Council of Canada 2009.
39. O'Riordan M. *Primary Care Teams: A GP Perspective* Dublin: Irish College of General Practitioners 201. Dublin.
40. Tinnelly M. *Occupational therapy in Primary Care: What are the current practices and perceptions of therapists in Ireland?* Galway: NUI Galway; 2011.
41. Hansson A, Friberg F, Segesten K, Gedda B, Mattsson B. Two sides of the coin-general practitioners' experience of working in multidisciplinary teams. *Journal of Interprofessional Care*. 2008;22(1):5-16.
42. O'Neill M CS. Partners in care: investigating community nurses' understanding of an interdisciplinary team-based approach to primary care. *J Clin Nurs* 2008 17(22):3004-11
43. Giltenane M, Kelly M, Dowling M. Public health nurses'(PHNs) experiences of their role as part of a primary care team (PCT) in Ireland. 2015. *Australian Journal of Advanced Nursing*, 2015; 32(3) 6-15.

44. Bellali T KM. Greek psychiatric care reform: new perspectives and challenges for community mental health nursing. *J Psychiatr Ment Hlt.* 2006;13(1):33-9.
45. Holt IG. Role transition in primary care settings. *Quality in Primary Care.* 2008;16(2):117-26.
46. Carlford S, Festin K. Primary health care staff's opinions about changing routines in practice: a cross-sectional study. *BMC Family Practice.* 2014;15(1):2. doi:10.1186/1471-2296-15-2.
47. McEvoy R, Ballini L, Maltoni S, O'Donnell CA, Mair FS, MacFarlane A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implement Science,* 2014;9(2).
48. May CR, Mair F, Finch T, MacFarlane A, Dowrick C, Treweek S et al. Development of a theory of implementation and integration: Normalization Process Theory. *Implementation Science.* 2009;4(1):29.
49. Collins C, O Riordan, M. The Future of Irish General Practice; ICGP Members Survey Dublin ICGP 2015.
50. Dillman DA, Tortora RD, Bowker D. Principles for constructing web surveys. In: *Joint Meetings of the American Statistical Association.* 1998. <http://134.121.51.35/dillman/papers/1998/PrinciplesforConstructingWebSurveys.pdf>. .
51. Thorpe C, Ryan B, McLean S, Burt A, Stewart M, Brown J et al. How to obtain excellent response rates when surveying physicians. *Family Practice,* 2009;26(1):65-8.
52. Boynton PM. Administering, analysing, and reporting your questionnaire. *BMJ* 2004;328(7452):1372-5. doi:10.1136/bmj.328.7452.1372.

53. Kennedy N, Armstrong C, Woodward O, W. C. Primary care team working in Ireland: A qualitative exploration of team member's experiences in a new primary care service. *Health and Social Care in the Community*, 2015; 23(4) 362-370.
54. May C, Finch T. Implementing, embedding, and integrating practices: An outline of Normalization Process Theory. *Sociology*. 2009;43(3):535-54. doi: 10.1177/0038038509103208
55. Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. *BMJ*. 2004;328(7451):1312-5. doi:10.1136/bmj.328.7451.1312.
56. Boyton P. Administering, analysing and reporting your questionnaire. *BMJ*. 2004;329(7461):323.
57. Burns KEA, Duffett M, Kho ME, Meade MO, Adhikari NKJ, Sinuff T et al. A guide for the design and conduct of self-administered surveys of clinicians. *Canadian Medical Association Journal*. 2008;179(3):245-52. doi:10.1503/cmaj.080372.
58. Sills SJ, Song C. Innovations in survey research an application of web-based surveys. *Social Science Computer Review*. 2002;20(1):22-30.
59. Hodinott SN, Bass MJ. The dillman total design survey method. *Can Fam Physician*. 1986;32:2366-8.
60. Dillman DA. *Mail and Internet surveys: The tailored design method--2007 Update with new Internet, visual, and mixed-mode guide*. John Wiley & Sons; 2011.
61. Dillman DA. *Mail and internet surveys: The tailored design method*. Wiley New York; 2000.

62. Dillman D, Groves B. Internet, mail and Mixed-Mode Surveys: The Tailored Design Method 3rd ed. Survey Research. 2011;34(833):635.
63. Kaplowitz MD, Hadlock TD, Levine R. A Comparison of Web and Mail Survey Response Rates. Public Opinion Quarterly. 2004;68(1):94-101.
64. Thorpe C, Ryan B, McLean SL, Burt A, Stewart M, Brown JB et al. How to obtain excellent response rates when surveying physicians. Family Practice. 2009;26(1):65-8. doi:10.1093/fampra/cmn097.
65. Walt G, Shiffman J, Schneider H, Murray SF, Brugha R, Gilson L. 'Doing' health policy analysis: methodological and conceptual reflections and challenges. Health Policy and Planning. 2008;23(5):308-17. doi:10.1093/heapol/czn024.
66. McDonald P. Response rates in general practice studies. The British Journal of General Practice. 1993;43(376):484.
67. Templeton L, Deehan A, Taylor C, Drummond C, Strang J. Surveying general practitioners: does a low response rate matter? The British Journal of General Practice. 1997;47(415):91-4.
68. Tinnelly M. Occupational therapy in primary care: what are the current practices and perceptions of therapists in Ireland? . Galway: National University of Ireland Galway; 2011.
69. O'Riordan M. Primary Care Teams: A GP Perspective Dublin: Irish College of General Practitioners, Dublin, 2011.
70. Wai-Sun Chan WD, Conroy R et al A multi-disciplinary primary care team consultation in a socio-economically deprived community: an exploratory randomised controlled trial. BMC Health Serv Res 2011;11(15).

71. Dale J, Potter R, Owen K, Parsons N, Realpe A, Leach J. Retaining the general practitioner workforce in England: what matters to GPs? A cross-sectional study. *BMC Family Practice*. 2015;16(1):140. doi:10.1186/s12875-015-0363-1.
72. Cook R. Paths to effective teamwork in primary care settings. *Nursing Times*. 1995;92(14):44-5.
73. Hultberg E-L, Lönnroth K, Allebeck P. Co-financing as a means to improve collaboration between primary health care, social insurance and social service in Sweden. A qualitative study of collaboration experiences among rehabilitation partners. *Health Policy*. 2003;64(2):143-52. doi:[http://dx.doi.org/10.1016/S0168-8510\(02\)00145-8](http://dx.doi.org/10.1016/S0168-8510(02)00145-8).
74. Schepman S, Hansen J, de Putter ID, Batenburg RS, de Bakker DH. The common characteristics and outcomes of multidisciplinary collaboration in primary health care: a systematic literature review. *International Journal of Integrated Care*. 2015;15:e027.

## **Chapter 5: Paper 2: Implementing community participation via interdisciplinary teams in primary care: An Irish case study in practice<sup>10</sup>**

### **5.1 Abstract**

#### **Background:**

Community participation in primary care is enshrined in international and Irish health policy. However, there is a lack of evidence about how stakeholders work collectively to implement community participation within interdisciplinary teams; community perspectives are rarely captured and a theoretical underpinning for implementation of community participation in primary care is absent.

#### **Objective:**

To conduct a theoretically informed, multi-perspectival empirical analysis of the implementation of community participation via primary care teams (PCTs) in Ireland.

#### **Methods/Design/Participants:**

Participatory Learning and Action (PLA) focus groups and interviews were held with 39 participants across four case study sites within a nationally funded programme designed to enable disadvantaged communities to participate in primary care. Normalization Process Theory (NPT) informed data generation and analysis of

---

<sup>10</sup> Published in *Health Expectations*. 2018; 00:1-12. <https://doi.org/10.1111/hex.12692>. Accepted: 13 March 2018

how diverse stakeholder groups worked together to implement community participation via PCTs.

### **Results:**

The various stakeholders had a shared understanding of the value of community participation on PCTs. Motivations to get involved in this work varied, but were strong overall. Challenges to enacting community participation on PCTs included problems with the functioning of PCTs and a lack of clarity and confidence in the role of community representatives at PCT meetings. Informal appraisals were positive but formal appraisal was limited.

### **Discussion and Conclusion:**

The implementation and sustainability of community participation on PCTs in Ireland will be limited unless; (i) the functioning of PCTs is strong, (ii) there is increased confidence and clarity on community representatives' roles among all health care professionals, and (iii) more sophisticated methods for formal appraisal are used.

## 5.2 Introduction

Community participation in primary care has its origins in the Alma-Ata Declaration of 1978, which stated that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care”. It is defined as:

*a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change [1] (p. 10).*

Since then, the concept of involving patients and the public in healthcare planning has gained acceptance and is enshrined in health policy across a range of international settings including the UK [2, 3], Scotland[4, 5], Wales[6, 7], Canada[8, 9] and New Zealand [10].

There are examples internationally of individual and collective processes to implement community participation in primary care [11-17]. In recent years, collective processes have been adopted in several countries; for example, citizens’ juries [18] and patient participation groups [15, 16] in the UK, citizen juries [13] and community representatives on health service committees [19] in Australia, dialogue sessions[20] in Canada, mixed advisory committees (MACs) [21] in Italy and community participation in primary health care organisations [22, 23] in New Zealand.

In this paper we focus on collective participation in primary care, which can overcome the reductive individualistic approach to health care participation [21] and create a more efficient and effective health care system [24-28]. It has also been shown to enhance the delivery and uptake of health interventions to address health inequalities, [29-33] and increase community cohesion and leadership [32-35].

Despite this, international policy context and efforts to implement community participation in primary care, there are major gaps in our understanding of its purpose, processes and outcomes [33]. There is limited data across the multiplicity of stakeholder perspectives on implementing community participation in primary care in practice, and community perspectives are rarely captured [28]. Furthermore, there is a lack of evidence for how the various stakeholders work together in a primary care setting to implement community participation within interdisciplinary teams. Lack of clarity and agreement between stakeholder groups about the roles of community representatives remains a major obstacle to effective community participation [19, 36-38].

Although theory has been used to understand how far Patient and Public Involvement (PPI) was embedded within health-care research in certain areas, [39] there has been no use of theory to study community participation in practice despite the call for theoretically informed, empirical analysis of implementation to generate insights and transferrable lessons for community participation in primary care across settings [40]; this is a priority for research, policy and practice [33].

In Ireland, community participation in primary care became enshrined in health policy with the launch of the 2001 Primary Care Strategy. This strategy sought to transfer most health care provision into the community to be delivered by interdisciplinary Primary Care Teams (PCTs) [41]. PCTs were encouraged to ensure community participation in service planning and delivery. A greater input from the community and voluntary sector was proposed to enhance the advocacy role of PCTs [41].

Despite this, and other interim measures such as the National Strategy for Service User Involvement, [42] involvement of patients and communities in the development and running of PCTs is not routine practice across the country, [40, 43, 44] is hard to achieve, [45] and is generally not regarded by service providers as an important resource for PCTs [46]. Therefore, the aforementioned gaps in international literature are also relevant to the Irish context [44, 47].

### **5.3 Rationale for this study**

The aim of this study was to address these international and national gaps in knowledge and to conduct a theoretically informed, multi-perspectival empirical analysis of the implementation work that has taken place in Ireland to embed a programme of community participation in primary care (known as the Joint Initiative). This paper focuses on the implementation of community participation on PCTs.

## **5.4 Method**

### **5.4.1 Study context**

This study took place within the Irish primary health care context following the end of a nationwide funded initiative – the Joint Initiative (JI) – to support community participation in primary care.

As a function of the JI, a range of community participation activities were developed including community needs assessment, health promotion and mental health awareness programmes, and community representation in the development of local primary care services [43, 48] As mentioned above, the focus of this paper is on collective community participation processes on PCTs in Ireland.

### **5.4.2 Study design**

The analysis in this paper is drawn from a larger qualitative retrospective case study (2011–2014) of the JI programme. The design of the study was in accordance with Yin’s recommendation for use of case studies to explore a phenomenon within its real-life context [49].

### **5.4.3 Sampling and recruitment**

Following the principles of purposeful sampling, [50] and in consultation with the external consultant who had evaluated the JI [43], four case study sites were chosen from the 19 JI demonstration projects in order to represent the geographical spread of the projects, the level of experience with community participation, the various

populations involved, and the “successful” and “less successful” interactions with PCTs (see Table 5.1).

**Table 5.1: Case study sites and research participants**

| <b>Case Study (CS) Site/Joint Initiative (JI) Project description</b>   | <b>Experience of interaction with Primary Care Teams (PCT) at point of recruitment</b>  | <b>Research study participants</b>  | <b>Employment status</b>                  | <b>Data generation method used Participatory Learning and Action (PLA) focus group or interview</b> |
|---|---|---|---|---|
| <p><b>CS Site 1:</b> This case study site was a migrant health forum JI project which interacted with the PCT around health issues relevant to migrants in a rural town with high deprivation and a large migrant population. The project developed a model of community participation for migrant communities based on community development principles.</p> | <p>The migrant group reported experiencing difficulties communicating with the PCT and did not achieve the envisaged involvement with the PCT. Participants reported that they felt failure in relation to community participation on PCTs.</p> | <p>Total no. of study participants N = 5</p> <p>Community representatives on migrant health forum (n = 3)</p> <p>Project co-ordinator (n = 1)</p> <p>Health Service Executive (HSE) policy personnel: Programme Manager (n = 1)</p> | <p>Unpaid</p> <p>Paid</p> <p>Paid</p>     | <p>PLA focus group</p> <p>Interview</p> <p>Interview</p>  |
| <p><b>CS Site 2:</b> This case study site was a JI project with a large network of people involved in community participation and primary care in a rural area with low-density population.</p>   | <p>This group had a long history of working in the area of community participation and had good experiences of</p>  | <p>Total no. of study participants N = 22</p> <p>Community Representatives on PCT or Community</p>  | <p>Paid (n = 6)</p> <p>Unpaid (n = 9)</p> | <p>PLA focus groups</p>   |

| <b>Case Study (CS) Site/Joint Initiative (JI) Project description</b> | <b>Experience of interaction with Primary Care Teams (PCT) at point of recruitment</b>   | <b>Research study participants</b>  | <b>Employment status</b>  | <b>Data generation method used Participatory Learning and Action (PLA) focus group or interview</b> |
|---|--|---|---|---|
|   | enacting community participation on PCTs and with the larger primary care network. There was reported successful interaction with the PCT. | Health Forum (n = 16)<br>HSE professionals:<br>HSE Social Inclusion Manager (n = 1)<br>HSE policy personnel: Programme Manager (n = 1)<br>Primary Care Development Officer (n = 1)<br>GPs (n = 3) | Unknown (n = 1)<br><br>Paid<br><br>Paid<br><br>Paid<br><br>Paid | Interview<br><br>Interview<br><br>Interview<br><br>Interview  |

| <b>Case Study (CS) Site/Joint Initiative (JI) Project description</b>  | <b>Experience of interaction with Primary Care Teams (PCT) at point of recruitment</b>   | <b>Research study participants</b>  | <b>Employment status</b>                            | <b>Data generation method used Participatory Learning and Action (PLA) focus group or interview</b> |
|--|--|---|---|---|
| <p><b>CS Site 3:</b> This case study site was a large JI inner city regeneration community health project, working with disadvantaged inner city communities. This was an area with high levels of poverty, disadvantage and health inequalities. There were a large number of community groups and projects up and running in the area.</p>           | <p>The case study site had engaged widely with groups and projects as well as with the PCT. This site had varied community participation activities across a number of health initiatives. Reported mixed success with interacting with the PCT.</p> | <p>Total no of study participants N = 8<br/> Community Representatives/Community health workers (n = 4)<br/> Project Coordinator (n = 1)<br/> HSE professionals:<br/> PCT Social Worker (n = 1)<br/> Occupational Therapy (OT) Manager PCT formerly PCT Manager (n = 1)<br/> PCT OT (n = 1)</p> | <p>Paid<br/> Paid<br/> Paid<br/> Paid<br/> Paid</p> | <p>PLA Focus groups<br/> Interview<br/> Interview<br/> Interview</p>                                |
| <p><b>CS Site 4:</b> This case study site was a JI Local Development Partnership Project in a rural town with a history of working with disadvantaged communities across the community, voluntary and statutory sectors. This site had experience and expertise in community consultations and addressing rural isolation and health inequalities.</p> | <p>This site had reported good interaction with their PCT and with different community participation initiatives in the area.</p>  | <p>Total no of study participants N = 4<br/> Community Representatives/community activist (n = 1)<br/> HSE professionals:<br/> PCT Social Worker (n =1)<br/> Development worker (n =1)<br/> HSE policy personnel:<br/> Primary Care Development Officer (n = 1)</p>                             | <p>Unpaid<br/> Paid<br/> Paid<br/> Paid</p>         | <p>Interview<br/> Interview<br/> Interview<br/> Interview</p>                                       |

The research participants (n=39) were identified and invited to participate in the study via gatekeepers at the four case study sites. Gatekeepers were paid project coordinators at each site who communicated with community representatives and health service employees and managers about the study and extended the invitation to them to participate in focus groups or interviews.

Participants were categorised as follows:

- (i) Community representatives<sup>11</sup> who had been involved in the JI demonstration projects and had some experience of interacting with PCTs within this context (n=27)
- (ii) Health Service Executive (HSE)-employed health care professionals who were working in the PCTs and worked with the JI demonstration projects (n=5)
- (iii) HSE-employed service planners and policy makers who oversaw the development of PCTs and had been involved with the development and roll-out of the JI (n=4)
- (iv) General Practitioners (GPs) working with PCTs (n=3)

---

<sup>11</sup> Community representatives in this context were defined as: “individuals, who are ‘representing’, representative, and/or ‘consultative’ of one or more populations or affinity groups. They can be stakeholders, opinion leaders, organisers and advocates. They serve as a platform and channel for information and voices of community, communicating ideas and concepts between community and health and social services and who hold people and processes accountable” [42] (p. 34).

## 5.5 Ethical approval

The Irish College of General Practitioners (ICGP) in Ireland provided ethical approval for this study.

## 5.6 Data generation

We employed Normalisation Process Theory (NPT) to inform data generation and analysis. See Box 5.1.

### Box 5.1: Normalisation Process Theory (NPT) theoretical constructs

NPT consists of four constructs designed to explain how stakeholders understand, buy into, enact and appraise a new practice.

NPT has been applied in several areas of health services research and has proved useful to enhance understanding of implementation journeys of a variety of interventions and innovations in health care settings, [63, 70] from a range of perspectives [61, 63, 69]. In this case, NPT allowed us to extract and explore data pertaining to the practice of community participation on Primary Care Teams (PCTs) across the range of stakeholders involved with the PCTs and JI projects. Data was deductively coded onto the four NPT constructs in NVivo [71] and further analysed via the lens of levers and barriers to implementation.

1. Coherence: Can stakeholders make sense of community participation on PCTs as a new way of working? Where coherence is strong there is a shared understanding

across all stakeholders of what this work will entail for individuals. There is common understanding about the value and purpose of this work.

2. Cognitive Participation: Will they engage with/“buy into” community participation on PCTs? Where cognitive participation is strong there are legitimate reasons for stakeholders to get involved and there are strong motivations for them to engage in this work. There are champions to support the work and resources available to get the work up and running.

3. Collective Action: What do stakeholders need to enact community participation on PCTs in daily practice? Where collective action is strong there is shared understanding about roles and responsibilities among stakeholders, there are resources available and structures in place to support the work in day to day practice and there are good relationships between and across stakeholders which support the work.

4. Reflexive Monitoring: Can stakeholders formally or informally appraise the impact of community participation on PCTs? Where reflexive monitoring is strong, there is agreement that the work has resulted in benefits for individual and wider community, there are clear evaluation mechanisms in place and there is a shared understanding about what changes are required in structures to sustain and embed the work.

Participants were contacted via gatekeepers and chose their preferred method of data generation (i.e. semi-structured interviews or Participatory Learning and Action (PLA) focus groups). PLA focus groups and data generation methods [51, 52] were used with community representative groups where possible. PLA focus groups involve the use of PLA techniques with inherent visual and analytic techniques. They were valuable because they allowed community representatives' perspectives to be shared across and between participants and for preliminary data analysis to be conducted in a collaborative and participatory fashion [53, 54] see Box 5.2. These techniques have been previously used with migrants and people with aphasia [54-58].

**Box 5.2: Participatory Learning and Action (PLA) techniques used for data generation and analysis**

The techniques used were Flexible Brainstorming (FBS) for data generation and Card Sorts for co-analysis of data. The FBS is a technique used to generate as many ideas as possible related to the research question and recording them on a large chart. It is suitable for those with low literacy as there are options to use pictures from magazines, draw pictures or have the research team write or spell words for participants if needed. PLA materials included a shared blank flip chart sheet, coloured markers and coloured stickies, pens, paper, key words, symbols and pictures placed in the centre on a large table for easy access. Participants chose materials to communicate their emic experiences of enacting community participation on primary care teams. The **Card Sort** was used to begin the process of

thematic co-analysis of the data developed in the Flexible Brainstorm. All information placed on the chart was organised by asking “*what ideas belong together? How would you organise these so that they can be organised into meaningful ‘bundles’*”? Participants moved the material on the chart into themes all the while explaining why these ideas belonged together and cross checking with each other that they were satisfied with this organisation of ideas.

Community representatives chose focus groups as their preferred method of data generation as these research sessions were held to coincide with their usual scheduled meetings, which was convenient and time efficient. Community representatives also indicated that it was a welcome means to reflect together on their community participation practices and their shared experiences of interacting with the PCT.

Interviews were favoured by health care professionals, GPs and HSE service planners and policy makers, allowing the participants to speak within their own conceptualisation of the phenomenon of community participation in primary health care and to make this explicit [59]. They were more convenient for this cohort of participants as the interviews were scheduled at a time and location suited to the individual and did not interrupt their busy schedules of work.

Gathering data from both focus groups and interviews provided rich narrative accounts which were analysed for shared and differential perspectives and

experiences between and among the participant groups, and across and between case study sites (Table 5.1).

## **5.7 Data analysis**

All interviews and focus groups were recorded and fully transcribed for analysis.

Participants chose a pseudonym to maintain anonymity.

Two researchers were involved in the focus groups, ET and RME. ET undertook all interviews. Data analysis for the wider project pertaining to community participation in primary health care was led by ET and deliberated in data analysis meetings with AMF and RME.

Data analysis for this paper specifically focused on data pertaining to community participation on PCTs and was led by ET. Analysis was then discussed and developed with AMF and AH.

Deductive data analysis [71] was informed by Normalisation Process Theory (NPT) using Nvivo. While there were different data generation methods used, with implications for group reflection (focus groups) versus individual conceptualisation (interviews), data from both methods resonated with the four constructs of NPT. This indicates that the data generation methods did not impact on the conceptual nature of the results.

Findings per construct were analysed asking ‘how strong is the implementation of community participation in PCTs?’ There is no recognised system for this layer of NPT analysis. Therefore, a working definition for strong implementation was

developed by the research team (see Box 5.1) and was used as a benchmark to classify the implementation as strong, medium or weak (see Table 5.2).

Codes ascribed to participants include pseudonym, data generation method, employment status and case study site, e.g. *John Walsh, Interview, Paid Primary Care Development Worker, CS Site 4*.

### **5.7.1 Quality and rigour**

Several steps were taken to increase the quality and rigour of our results [60]. These included; recording of reflective notes during fieldwork, regular data analysis clinics for NPT analysis, member checking with participants via email and face-to-face meetings as well as feedback sessions with participants. NVivo 10 software was used to facilitate data coding and analysis and sharing data across the research team.

These steps were continued until there was sufficient, thick description in the data, that is, until data saturation had been reached [60].

## **5.8 Results**

Participants ( $n = 39$ ) were paid and unpaid community representatives ( $n = 27$ ); HSE health care professionals working on PCTs ( $n = 5$ ); HSE service planners and policy makers who oversee the development of PCTs ( $n = 4$ ); and GPs ( $n = 3$ ) (see Table 5.1).

**Table 5.2: Levers and barriers to community participation on Primary Care Teams (PCTs) using Normalisation Process**

**Theory (NPT) constructs to evaluate implementation; synthesis of findings across research sites**

| NPT construct (n = 4) (May and Finch 2009)  | Lever   | Barrier  | Status   |
|---|---|--|----------|
| <i>Construct 1: Coherence<br/>Can stakeholders make sense of community participation on PCTs as a new way of working?</i>       | Shared views about potential value of community participation on PCTs across stakeholders directly involved in the Joint Initiative   | Lack of shared understanding by wider stakeholder community about the role of community reps on PCTs | Moderate |
| <i>Construct 2: Cognitive Participation<br/>Will stakeholders engage with/‘buy into’ community participation on PCTs?</i>       | Champions employed by Health Service Executive (HSE) drive this way of working forward<br><br>Existing positive relationships support buy-in<br>Personal motivations to empower communities enhance buy-in for community members<br><br>Fits with social determinants of health or professional ethos of team members |  | Strong   |
| <i>Construct 3: Collective Action<br/>What do stakeholders need to enact community participation on PCTs in daily practice?</i> | Dedicated resources and funding for paid role to coordinate the work  | Time-consuming to plan and co-ordinate across stakeholder groups                                     | Moderate |

| NPT construct (n = 4) (May and Finch 2009)  | Lever  | Barrier   | Status      |
|---|--|---|-------------|
|   |  | <p>Lack of PCT readiness and PCT functioning</p> <p>Lack of clarity and confidence about community representatives' roles at PCT meetings</p> <p>Lack of respect by some PCT members for role of the community representative</p> |             |
| <p><i>Construct 4: Reflexive Monitoring</i><br/> <i>Can stakeholders formally or informally appraise the impact of community participation on PCTs?</i></p> | <p>Informal evaluations are broadly positive</p> <p>Leads to increased awareness about primary care services</p> | <p>Formal HSE Key Performance Indicator (KPI) is limited and does not cover the complexity and value of the work</p> <p>Uncertainty about the sustainability of community participation on PCTs.</p>                              | <p>Weak</p> |

### **5.8.1 Coherence: Can stakeholders make sense of community participation on PCTs as a new way of working?**

All participants in the study considered that community participation on PCTs was about meaningful reciprocal relationships between stakeholders to represent the voice of the community in primary health care delivery generally and at the PCT meetings more specifically.

*And their [community reps'] role would be I suppose to act as a voice for the community, with regards to needs and ... ultimately maybe to have some impact on shaping services. (John Walsh, Interview, Paid Development Worker, CS Site 4)*

In particular, managers and policy makers saw this as a very valuable mechanism for consultation with communities. There was a general consensus that the role of community representatives was to feed ideas to the PCT about service needs of the community.

The community representatives saw the value of their role as a means to empower community members, find their voice and encourage participation. They saw their role as a catalyst for change in the dynamic of PCTs.

*Just another thing that should be on there is something like empowerment. Because I think even through involvement in community forums and that people are coming into those community forums that might not have had any community participation prior to that involvement. So you know its*

*empowering them to find their own voice within the community. (Midge, Focus group (FG), Unpaid CHF Member, CS Site 2)*

However, participants in the study agreed that there is a lack of shared understanding among the wider network of PCT members and the wider community in their area about community participation on PCTs and what the role of community representatives entailed.

*I'm not too sure that people [PCT members] attending the meetings really understand why they [community representatives] are there. (Mary, FG, Paid PCT Community Rep, CS Site 2)*

For GPs, the introduction of community representatives on PCTs elicited a fear that they would lose control of their work, and this was a concern for them at the start of the process.

*But yet when it was first mooted then that you know people were going to go out and find out what did people actually want, we thought ... well are we going to lose control of our work? (Dock, Interview, GP, CS Site 2)*

Overall coherence was moderate. This meant that stakeholders who were closely involved in the JI across roles and case study sites generally saw the value of community participation on PCTs but there was not a shared understanding about what this work would entail in the wider network of stakeholders.

### **5.8.2 Cognitive participation: Will stakeholders engage with/“buy into” community participation on PCTs?**

Buy-in to this way of working for community representatives happened because they were invited to be a representative on the PCT by “champions of the JI” who were known to them. This was usually a community development worker, project coordinator or PCT work colleague. These “champions” were described as being passionate and committed.

*But can I say Bree [paid community health forum support worker] ... is very passionate in the work she does and I'm sure we'd all agree and she puts in an awful lot of work and you know only for you Bree you know she's a great, you've great management skills. You know, I think only for you, I probably wouldn't be still here. (Corrina, FG, Paid CHF Support Worker and PCT Rep, CS Site 2)*

They also had personal motivations and became involved because they lived locally and had a vested interest in the area. It was also an opportunity to share information with the PCT about particular community projects with which they were involved.

*I felt that I had a contribution to make, when they asked me that night why do you want to be a rep and I said I was hoping to give [something back to the community]. I had worked on a mental health group for a long time before it, and even though I knew it wouldn't be just representing in the mental health I felt I could be a voice for them [the community] as well on the team [PCT]. (Tess, FG, Unpaid PCT Community Rep, CS Site 2)*

Buy-in for health professionals was also influenced by champions of the JI and existing relationships which supported the set-up and roll-out of PCTs.

*So those relationships were there, and we had done an initial bit of work and I guess maybe there was reasonably high expectations of the roll-out of primary care teams and maybe the impact it would have and maybe the opportunities for communities to become involved. (John Walsh, Interview, Paid Primary Care Development Worker, CS Site 4)*

For some health professionals, it fitted with the community development model/social determinants of health and their philosophy of work in a paid professional role.

*Actually primary care is a huge opportunity for social work to go back to its roots about being a community social worker, and I suppose that's one of the reasons I was particularly interested in, in primary care and in this project was that it is about those, those skills and values that social work began with, is actually engaging local communities in having a say in what they want in their own health and their own wellbeing. (Thomas, Interview, Paid Social Worker PCT, CS Site 4)*

Motivation for policy makers was that community participation on PCTs connects with Primary Care Strategy and therefore “activates” the policy on the ground.

*Well, I suppose it goes back to the primary care team involvement and the national primary care strategy which obviously advocates this element*

*(community participation on PCTs). (Paddy, Interview, Paid Primary Care Development Officer, CS Site 1)*

Cognitive participation was strong. This means that stakeholders from all groups bought into this way of working because they were invited by champions, and existing relationships supported the work. There were also complementary, differential motivations for community and professional participants that fuelled interest and responsiveness to invitations to get involved in the JI.

### **5.8.3 Collective action: What do stakeholders need to enact community participation on PCTs in daily practice?**

All participants talked about the importance of a paid role to coordinate this work.

*I don't think it would happen unless somebody specifically has that role or mandate to do it because it's just understood that it will happen. (Shell, Interview, Paid Migrant Health Forum Coordinator, CS Site 1)*

The training provided was also valued.

However, despite these levers, participants across sites and across stakeholder roles emphasised the barriers they experienced while trying to get this way of working into practice.

First, participants in local management roles talked about extensive planning and consultation that had to take place to maintain everyone's involvement and to organise what was going to happen, where and when:

*People don't necessarily understand the amount of detail or planning or consultation that's involved in this, the HSE management or people nationally wouldn't understand that type of thing and they wouldn't understand the level of detail and the amount of time and the buy-in and the commitment and how long it takes. (Paddy, Interview, Paid Primary Care Development Officer, CS Site 1)*

Second, all participants irrespective of role and across sites felt that the PCTs were not at a stage of development for community participation to operate effectively. All participants agreed that this was a major barrier to the enactment of community participation on PCTs.

*So the primary care team itself wasn't functioning, the business meeting wasn't functioning very effectively, it was very new. So there wasn't really the channel of communication about what was being expected in there and then what they can do, what they were expected to do. What happened was the primary care team continued not to function very well for a good long time, probably three years I should think after it formed. (Lydian, Interview, Paid Community Support Worker, CS Site 2)*

GPs spoke about their frustration with PCT working itself, the different styles of working involved and the challenge of this for them.

*Looking back, I mean there was a lot of problems with it [PCT working]. Because we had meeting after meeting after meeting where we were able to make a decision here and now, if we met with the dietician or the different branches from the hospital we could make a decision about where we go here and now as GPs. But they couldn't, there was line managers, meetings about meetings about meetings. (Dock, Interview, GP, CS Site 2)*

Third, GPs were also frustrated about the community development style of working, which they felt took up a lot of time and didn't necessarily need their input.

*Yeah, I wouldn't have the resources to travel. My own role I did it purely on a voluntary basis, I had to make up the time elsewhere. I was rushing, like there was tea and sandwiches provided which was great so I didn't have to miss my lunch, but it was a bit of a chore. (Tom, Interview, GP, CS Site 2)*

Where community representatives did get to participate in PCT meetings, there was a lack of clarity among some health professionals about the precise role of the community representatives at those meetings. There were misunderstandings about issues such as loss of confidentiality at meetings, and what the community representatives were trying to achieve.

*But we were trying to kind of get across the idea that the community reps weren't here to discuss specific clients, they were here to discuss broader*

*issues and they could bring stuff to us and we could advise them of things that they could share with the community, but the team wasn't ready, that's the reality. (Thomas, Interview, Paid Social Worker PCT, CS Site 4)*

Furthermore, the community representatives felt their role was tokenistic.

*I suppose the only other negative impact ... a negative thing would be I don't think we are seen as equal partners by the clinicians. And that is a difficulty. (Midge, FG, Unpaid CHF Member, CS Site 2)*

Management felt that GPs did not appreciate the role of community representatives on the PCT.

*I think the GPs particularly just were really not, they were quite happy to let us do it and maybe partake in it but they didn't see, I don't think they really saw the value or the, what this would achieve. That would be sort of my, there would be a standard approach really for my sense of it, I think they feel it's a bit fluffy and it's a bit and nothing really happens. (Carol, Interview, Paid Primary Care Development Officer, CS Site 4)*

However, for GPs this “distance” was explained by their view of community participation in primary care more generally. They did not feel the need to interfere with the work of the community and just allowed community representatives to get on with it.

*So a lot of the over 50's club and they had the community bus run for the elderly, so these services were run totally [by the community], we didn't really have much to do with them. We would support them and say yes it's a good idea, but the rest as a team ran with it themselves. (Dock, Interview, GP, CS Site 2)*

Collective Action was moderate. This means that available resources and training were important levers for enacting community participation on PCTs. However, the PCTs were not sufficiently developed for community participation to operate effectively. This impacted on relationships in the team, and community representatives did not feel that they were viewed as equal partners at the PCT meetings.

#### **5.8.4 Reflexive monitoring: Can stakeholders formally or informally appraise the impact of community participation on PCTs?**

All participants agreed that community participation on PCTs is hard to evaluate or measure. Community participation on PCTs was measured formally by a Key Performance Indicator (KPI) (a count of the number of community representatives on the PCT) by the HSE nationally. However, this metric was considered by most participants as being very limited. It did not capture the breadth and variety of activities that comprise community participation activities. This was cited as problematic particularly among local management.

*There's also the fact that there's lots of activities we are working on with primary care teams that don't form part of the official statistics ... but it might not count that they went along and took part in a group activity, as part of say a health screening event at a football match. (T. Burnett, Interview, Paid PC Development Officer, CS Site 2)*

When people were asked to informally appraise the impact of community participation on PCTs, the biggest benefit cited across all stakeholders and case study sites was increased awareness about services available in the community and among HSE personnel about community projects and the role of community workers.

*Among the primary care team, it heightened the awareness of what was going on in the community. And then the flip side of that is that the community was more aware of the primary health care team and what they were about and how they functioned etc. (John Walsh, Interview, Paid Development Worker, CS Site 4)*

For many community representatives on an individual level, this work led to personal benefits such as empowerment. The training and skill development that they received supported their career paths. This was particularly evident for the migrant health forum group.

On a collective level, community representatives felt that community participation on PCTs improved service delivery for the local population, resulted in more efficient use of resources and connected GPs with their community.

*Yes, we had huge success within the community ... like the gardening and mental health programme, the green prescription, and different aspects of that, and that has been obviously through our involvement in the primary care team. That we've been able to channel some of the resources down in, you know we have that tangible success. (Tess, FG, Unpaid PCT Community Rep, CS Site 2)*

They also cited mutual learning for community representatives and clinicians on the teams. They educated clinicians about the value of community participation and this resulted in improved networking across community regions to share resources.

*The impact has been educating clinicians and GPs on the value of community participation. (Bree, FG, Paid CHF Support Worker and PCT Rep, CS Site 2)*

However, for some community representatives there was disappointment that nothing happened as a result of the work, and there was a sense of lost opportunity.

*Ah no, I suppose there was frank discussion but I would just see that we still, at the end of the day nothing has changed. (John, Interview, Unpaid Community Activist, CS Site 4)*

Similarly, GPs were generally less positive about this work and felt they had little to contribute to the community participation on PCTs process.

*My difficulty was while I hope I contributed a bit, I'm not too sure how much my contribution is relevant to these community groups really. (Tom, Interview, GP, CS Site 2)*

Across all participant groups there was uncertainty about the future of community participation on PCTs. There was agreement that it is a challenge to sustain this way of working. In particular, the lack of resources to sustain the PCTs was cited as a challenge for the future. The economic recession impacted the work and there were significant budget cuts, introduced around the time of fieldwork, which decimated the scope for continuing the work initiated by the JI and starting new projects in other settings.

*I mean recently with budget cuts and restraints on people, it's just not, it's something that makes it very difficult to achieve now. In the current environment I don't know how it could be achieved because people are so stretched that this is just something else that they have to do. (Shell, Interview, Paid Migrant Health Forum Coordinator, CS Site 1)*

Management in particular felt that this work needs to be built into professional roles and there needs to be more education about the practicalities of enacting this work.

*I think it's a challenge [the future of CP on PCTs] probably for both organisations now because as our resources diminish ... it becomes less of a focus as other priorities take heed ... I think people do value the importance of it but it just can get lost with everything else that's going on. (Carol, Interview, Paid PC Development Officer, CS Site 4)*

Reflexive monitoring was weak. This means that informal appraisals of community participation on PCTs were quite positive but it was hard to formally evaluate or measure. The scope for sustaining the work and transferring lessons learned to other sites was considered to be very poor, particularly in the context of the economic recession that decimated resources.

## **5.9 Discussion and conclusions**

### **5.9.1 Summary of key findings**

There was a shared understanding about the idea and potential value of community participation on PCTs among stakeholder groups involved in the JI across roles and case study sites, but this did not hold across the wider network of stakeholders on PCTs and community.

Stakeholders across groups bought into this way of working because they were invited by passionate and convincing “champions”. Existing relationships and complementary motivations also fuelled buy-in.

There were positive examples of enacting community participation on PCTs, supported by available resources and training. However, it was challenging because it is time-consuming work for those in management roles. Furthermore, it was taking place against the background of poorly functioning PCTs as well as confusion and concern about community representatives' role at PCT meetings. This thwarted health care professionals' confidence in the work and inhibited meaningful engagement experiences for community representatives.

There were informal, positive appraisals of impact from most stakeholder groups. There was also consensus that impacts are difficult to capture formally and that sustaining and transferring the work that had started was going to be very difficult in the context of the economic recession.

### **5.9.2 Methodological critique**

This study is a snapshot of a funded national initiative introduced in Ireland at a particular point in time and represents findings from four case study sites within this larger initiative. We recognise that in this study both the case and its context were changing over time. The national initiative began during an economic boom and our fieldwork took place after a global recession that impacted considerably on Irish health care generally and the scope for community participation in particular.

A strength of this study is that it adds the unique voice of community representatives that is absent from the literature, [28] using methods that were valuable to elicit

shared and differential views about community participation experiences. Also, by drawing on a theoretical framework for implementation, we have highlighted the levers and barriers to implementation of community participation on PCTs across the multiplicity of stakeholder perspectives not reported elsewhere. Illuminating these levers and barriers across the various stakeholder perspectives using a theoretical framework offers the opportunity for comparable analyses of similar initiatives in other health care jurisdictions [61-63].

In relation to the multi-perspectival analysis, the participation of more GPs in the fieldwork would have been beneficial. GPs are core members of PCTs and vital to their effective functioning. Acceptance of community representatives at PCT meetings may be dependent on their attitude. Indeed, the fact that recruitment of GPs was only possible in one case study site may tell us something about why community representatives felt they were not respected in this role by health professionals and GPs in particular, although this would need further investigation.

### **5.9.3 Comparison with literature**

Similar to findings about PPI in research [39], effective community participation on PCTs is supported by shared understanding of the moral and methodological purposes of participation, a key co-ordinator, a positive and engaged team based on relationships established and maintained over time and a proactive and systematic approach to evaluation. In keeping with the international literature, there was general enthusiasm for community participation in planning primary health care via PCTs across stakeholders in this Irish study [19]. The potential benefits of community

participation on PCTs, such as improved service delivery and increased awareness, were recognised [25-28][64].

Visionary leaders who are committed to working with communities were an essential ingredient of encouraging buy-in and commitment to community participation.

Community workers acted as what have been identified elsewhere in the literature as “boundary spanners”, [65, 66] which means that local people were drawn into the process and, with increased confidence, became advocates and translated and mediated between local people and professionals [22, 65].

However, despite a considerable investment of resources through the JI to build capacity for this work, clarity and agreement between different stakeholder groups about the roles of community representatives was problematic, as cited elsewhere,[36-38] and GP concerns about the potential for negative impact on their practices was reported [22]. From an NPT perspective, this lack of clarity and confidence will undermine the workability of community participation in PCTs in practice. The challenge seems to be in reaching the full network of relevant stakeholders to enhance understanding, engagement and readiness for community participation on PCTs.

#### **5.9.4 Implementation and Enactment**

It is not possible to consider community participation outside a political context [67].

This analysis has highlighted that there were two political innovations at play in

Ireland at the time of this study: the introduction of primary care teams via the primary care strategy and the introduction of community participation on PCTs via the Joint Initiative. The problems with full implementation of interdisciplinary team working are not unique to Ireland [68].

From an NPT perspective, in this analysis, while this dual interplay did not seem to impact so much on *sense-making* or *engagement* processes, it clearly impacted on the readiness of PCTs to *enact* community participation on PCTs. Put simply, community participation on PCTs, without a proper PCT structure, is hard to enact. Participants in this study were adamant that PCTs should be fully resourced and running effectively before community participation is introduced.

The implementation and sustainability of community participation in PCTs in Ireland will be limited unless the functioning of PCTs themselves is stronger, there is increased confidence and clarity on community representatives' roles among all health care professionals, and more sophisticated methods for formal appraisal are employed. Future research could investigate how training in methods to enact community participation on PCTs could enable shared understanding to be achieved and clarity of roles to be developed. Evaluation strategies could be built into team processes early on to investigate impact and outcomes on PCT activities. Evaluative frameworks that capture a range of outcomes including unforeseen ones should also be developed.

## 5.10 Acknowledgements

We acknowledge the contribution of the following to the wider study and thank them for their support: Jane Pillinger, Rachael King, participants and gatekeepers.

## 5.11 References

1. WHO, *Community participation in local health and sustainable development: approaches and techniques*. 2002, WHO: Geneva.
2. Department of Health, *Patient and public involvement in the NHS 1999*, UK Department of Health: London.
3. Department of Health, *Involving patients and the public in healthcare: response to the listening exercise*, Department of Health, Editor. 2001: London.
4. Scottish Health Council, *Promoting, supporting and developing public involvement in primary care 2013*, The Scottish Health Council.
5. Scottish Consumer Council, *Designed to Involve: public involvement in the new primary care structures*. 1999: NHS Management Executive, the Scottish Association of Health Councils and the Scottish Consumer Council.
6. Welsh Government, *Parliamentary Review of Health and Social Care in Wales Interim Report*. 2017, Welsh Government.
7. Welsh Government, *Our plan for a primary care service for Wales up to March 2018*, 2014, Welsh Government.
8. Health Canada, *Health Canada Policy Toolkit for Public Involvement in Decision Making*. 2000, Health Canada: Ottawa, Canada.

9. Health Council of Canada, *Teams in Action Primary Health Care Teams for Canadians*. 2009, Health Council of Canada: Toronto
10. Neuwelt, P., *Community participation in primary care: what does it mean 'in practice'?* J Primary Health Care, 2012. **4**. 30-38.
11. Ruano, A.L., M.S. Sebastián, and A.K. Hurtig, *The process of social participation in primary health care: the case of Palencia, Guatemala*. Health Expect, 2014. **17**(1): p. 93-103.
12. Barry , M.J. and S. Edgman-Levitan *Shared decision making — The pinnacle of patient-centered care*. New Eng Med, 2012. **366**(9): p. 780-781.
13. Bath, J. and J. Wakerman, *Impact of community participation in primary health care: what is the evidence?* Aust Prim Health, 2013. 21:2-8.
14. Gooberman Hill, R., J. Horwood, and M. Calnan, *Citizens' juries in planning research priorities: process, engagement and outcome*. Health Expect, 2008. **11**(3): p. 272-281.
15. Brown, I., *Patient participation groups in general practice in the National Health Service*. Health Expect, 1999. **2**(3): p. 169-178.
16. Wilkie, P., *Patient participation groups in general practice: building better partnerships*. 2016, Brit Gen Pract. p. 548-549.
17. Coulter, A., *Patient engagement—what works?* Ambul Care Manage, 2012. **35**(2): p. 80-89.
18. Gooberman-Hill, R., J. Horwood, and M. Calnan, *Citizens' juries in planning research priorities: process, engagement and outcome*. Health Expect, 2008. **11**(3): p. 272-281.

19. Nathan, S., L. Johnston, and J. Braithwaite, *The role of community representatives on health service committees: staff expectations vs. reality*. Health Expect, 2011. **14**(3): p. 272-284.
20. Maxwell, J., S. Rosell, and P.-G. Forest, *Giving citizens a voice in healthcare policy in Canada*. British Medical Journal, 2003. **326**(7397): p. 1031.
21. Serapioni, M. and N. Duxbury, *Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees*. Health Expect, 2014. **17**(4): p. 488-499.
22. Neuwelt, P., et al., *Assessing and developing community participation in primary health care in Aotearoa New Zealand: a national study*. New Zeal Med J (Online), 2005. **118**(1218).
23. King, H.A., *The primary health care strategy*. 2001, Ministry of Health: Wellington. New Zealand.
24. Van de Bovenkamp, H.M., M.J. Trappenburg, and K.J. Grit, *Patient participation in collective healthcare decision making: the Dutch model*. Health Expect, 2010. **13**(1): p. 73-85.
25. Tempfer, C.B. and P. Nowak, *Consumer participation and organizational development in health care: a systematic review*. Wiener Klin Wochenschr, 2011. **123**(13-14): p. 408-414.
26. Sarrami-Foroushani, P., et al., *Key concepts in consumer and community engagement: a scoping meta-review*. BMC Health Serv Res, 2014. **14**(1): p. 250.
27. Crawford, M.J., et al., *Systematic review of involving patients in the planning and development of health care*. BMJ, 2002. **325**(7375): p. 1263.

28. Preston, R., et al., *Community participation in rural primary health care: intervention or approach?* Aust J Prim, 2010. **16**(1): p. 4-16.
29. Assai, M., S. Siddiqi, and S. Watts, *Tackling social determinants of health through community based initiatives.* BMJ, 2006. **333**(7573): p. 854-856.
30. National Institute for Health and Care Excellence. *Community engagement: Improving health and wellbeing and reducing health inequalities.* 2016 [cited accessed 11th Jan 2018; Available from: <https://www.nice.org.uk/guidance/ng44/resources/community-engagement-improving-health-and-wellbeing-and-reducing-health-inequalities-1837452829381>.
31. WHO, *Primary Health Care: Now More Than Ever.* 2008, WHO Geneva
32. Draper, A.K., G. Hewitt, and S. Rifkin, *Chasing the dragon: developing indicators for the assessment of community participation in health programmes.* Social Sci Med, 2010. **71**.
33. Kenny, A., et al., *Community participation for rural health: a review of challenges.* Health Expect, 2015. **18**(6): p. 1906-1917.
34. Kegler, M.C., B.L. Norton, and R.E. Aronson, *Strengthening community leadership: evaluation findings from the California Healthy Cities and Communities program.* Health Promotion Practice, 2008. **9**(2): p. 170-179.
35. Gaventa, J. and G. Barrett, *Mapping the outcomes of citizen engagement.* World Development, 2012. **40**(12): p. 2399-2410.
36. Fudge, N., C.D. Wolfe, and C. McKeivitt, *Assessing the promise of user involvement in health service development: ethnographic study.* BMJ, 2008. **336**(7639): p. 313-317.

37. Hogg, C. and C. Williamson, *Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees*. Health Expect, 2001. **4**(1): p. 2-9.
38. Hogg, C.N., *Patient and public involvement: what next for the NHS?* Health Expect, 2007. **10**(2): p. 129-138.
39. Wilson, P., et al., *ReseArch with Patient and Public invOvement: a RealisT evaluation—the RAPPORt study*. 2015, NIHR.
40. McEvoy, R. and A. MacFarlane, *Community participation in primary care in Ireland: the need for implementation research*. Primary Health Care Res, 2013. **14**(02): p. 126-139.
41. Department of Health and Children, *Primary Care: A New Direction*. 2001, Department of Health and Children: Dublin.
42. Department of Health and Children, *Strategy for Service User Involvement in the Irish Health Service 2008-2013*. 2008, Health Services Executive and Department of Health and Children: Dublin.
43. Pillinger, J., *Formative Evaluation of the Joint Community Participation in Primary Care Initiative*. 2010, Department of Community, Equality & Gaeltacht Affairs and Health Service Executive: Dublin
44. O'Reilly, F., *Reality or rhetoric? Community Involvement in Primary Care in North Inner City Dublin*, PhD thesis, *Department of General Practice, Royal College of Surgeons in Ireland*, 2012: Dublin.
45. O'Sullivan, M., W. Cullen, and A. MacFarlane, *Primary care teams in Ireland: a qualitative mapping review of Irish grey and published literature*. Irish J Med Sci, 2015. **184**(1): p. 69-73.

46. Tierney, E., et al., *Do primary care professionals agree about progress with implementation of Primary Care Teams:-results from a cross sectional study.* BMC Family Practice, 2016: p. 1-23.
47. Ní Riain, A., *Implementation of the primary care strategy 2005: a study of the experiences of team work among members of primary care teams in County Wexford in 2011.* Irish Med J 2012. **105**(2): p. 60-61.
48. MacFarlane, A., Tierney, E. McEvoy, R., *A Framework for Implementation of Community Participation in Primary Health Care.* 2014, Univeristy of Limerick and Health Service Executive: Limerick.
49. Yin, R.K., *Case study research; design and methods.* 2014, Los Angeles: Sage.
50. Patton, M., *Purposeful sampling.* Qualitative evaluation and research methods, 1990. **2**: p. 169-186.
51. Chambers, R., *Participatory Rural Appraisal (PRA): Analysis of experience.* World Dev, 1994. **22**(9): p. 1253-1268.
52. O'Reilly-de Brún, M., & de Brún, T., *Participatory Learning and Action (PLA) Training Manual – internal document.* 2011, Centre for Participatory Strategies (CPS): Ross Wood Clonbur Co. Galway Ireland.
53. O'Reilly-de Brún M, de Brún, T, O'Donnell CA, et al., *Material practices for meaningful engagement: An analysis of participatory learning and action research techniques for data generation and analysis in a health research partnership.* Health Expect, 2017. **00**: p. 1-12.
54. de Brún, T., et al., *Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an analysis*

- of stakeholders' experiences*. Research Involvement and Engagement, 2017. **3**(1): p. 28.
55. O'Reilly-de Brún, M., et al., *Involving migrants in the development of guidelines for communication in cross-cultural general practice consultations: a participatory learning and action research project*. BMJ open, 2015. **5**(9): p. e007092.
56. MacFarlane, A., et al., *Healthcare for migrants, participatory health research and implementation science—better health policy and practice through inclusion. The RESTORE project*. The European Journal of General Practice, 2014. **20**(2): p. 148-152.
57. Mc Menamin, R., E. Tierney, and A. Mac Farlane, *Addressing the long-term impacts of aphasia: how far does the Conversation Partner Programme go?* Aphasiology, 2015. **29**(8): p. 889-913.
58. Mc Menamin, R., E. Tierney, and A. Mac Farlane, *Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study*. Aphasiology, 2015. **29**(8): p. 914-938.
59. Bergen, A. and A. While, *A case for case studies: exploring the use of case study design in community nursing research*. J Adv Nurs, 2000. **31**(4): p. 926-934.
60. Creswell, J., *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. 2nd Edition ed. 2007: SAGE Publications.
61. May, C. and T. Finch, *Implementing, embedding, and integrating practices: An outline of Normalization Process Theory*. Sociology, 2009. **43**(3): p. 535-554.

62. Eccles, M., et al., *An implementation research agenda*. *Implement Sci*, 2009. **4**(1): p. 18.
63. McEvoy, R., et al., *A qualitative systematic review of studies using the normalization process theory to research implementation processes*. *Implement Sci*, 2014. **9**(2).
64. Ramsden, V.R., S. McKay, and J. Crowe, *The pursuit of excellence: engaging the community in participatory health research*. *Glob Health Promot*, 2010. **17**(4): p. 32-42.
65. Anderson, E., M. Shepherd, and C. Salisbury, *'Taking off the suit': engaging the community in primary health care decision-making*. *Health Expect*, 2006. **9**(1): p. 70-80.
66. Detmer, D., *Clinician-managers: the 'boundary spanners' of health services*. *J Health Serv Res Pol*, 2000. **5**: p. 197-198.
67. Rifkin, S.B., *Lessons from community participation in health programmes: a review of the post Alma-Ata experience*. *Int Health*, 2009. **1**(1): p. 31-36.
68. O'Reilly, P., et al., *Assessing the facilitators and barriers of interdisciplinary team working in primary care using normalisation process theory: an integrative review*. *PLoS One*, 2017. **12**(5): p. e0177026.
69. Finch, T.L., et al., *From theory to 'measurement' in complex interventions: methodological lessons from the development of an e-health normalisation instrument*. *BMC Med Res Methodol*, 2012. **12**(1): p. 1.
70. Murray, E., et al., *Why is it difficult to implement e-health initiatives? A qualitative study*. *Implementation Sci*, 2011. **6**(1): p. 1.

71. Pope, C., S. Ziebland, and N. Mays, *Analysing qualitative data*. BMJ, 2000.  
**320.**

## **Chapter 6: Paper 3: Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study<sup>12</sup>**

### **6.1 Abstract**

#### **Background:**

The involvement of patients and the public in healthcare has grown significantly in recent decades and is documented in health policy documents internationally. Many benefits of involving these groups in primary care planning have been reported.

However, these benefits are rarely felt by those considered marginalised in society and they are often excluded from participating in the process of planning primary care. It has been recommended to employ suitable approaches, such as co-operative and participatory initiatives, to enable marginalised groups to highlight their priorities for care.

#### **Methods:**

This Participatory Learning and Action (PLA) research study involved 21 members of various marginalised groups who contributed their views about access to primary care. Using a series of PLA techniques for data generation and co-analysis, we explored barriers and facilitators to primary healthcare access from the perspective

---

<sup>12</sup> Published in International Journal for Equity in Health (2016) 15:197 DOI 10.1186/s12939-016-0487-5. Received: 2 August 2016. Accepted: 25 November 2016

of migrants, Irish Travellers, homeless people, drug users, sex workers and people living in deprivation, and identified their priorities for action with regard to primary care provision.

**Results:**

Four overarching themes were identified: the home environment, the effects of the ‘two-tier’ healthcare system on engagement, healthcare encounters, and the complex health needs of many in those groups. The study demonstrates that there are many complicated personal and structural barriers to accessing primary healthcare for marginalised groups. There were shared and differential experiences across the groups. Participants also expressed shared priorities for action in the planning and running of primary care services.

**Conclusions:**

Members of marginalised groups have shared priorities for action to improve their access to primary care. If steps are taken to address these, there is scope to impact on more than one marginalised group and to address the existing health inequities.

**Keywords:**

Primary healthcare, Marginalised groups, Access, Participatory research, Equity, Patient and public involvement (PPI), Vulnerable groups, Hard to reach

## 6.2 Background

The concept of involving patients and the public in healthcare planning has gained acceptance in recent decades and is enshrined in health policy across a range of international settings [1–7]. The Alma-Ata Declaration of 1978 stated that *‘people have the right and duty to participate individually and collectively in the planning and implementation of their health care’*, and that effective primary healthcare *‘requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care’* [8]. This concept of participation continues to capture the attention of health policymakers and planners across both low- and high-income countries today [9–11] and the ‘co-production of health’ and the fostering of ‘equal and reciprocal’ interactions are now seen to be core attributes of health service design [12].

Many benefits of patient and community participation in healthcare planning have been reported, including the improved provision and uptake of initiatives to address health inequalities, the increased acceptance and effectiveness of healthcare services and closer attention to community priorities, and there is also evidence that participatory processes can increase community cohesion and leadership [13–18]. These benefits, however, are not experienced by all, and access to the processes of participation is difficult for many members of society deemed to be ‘marginalised’.

Marginalised groups have been defined as ‘populations outside of “mainstream society”’ [19] and ‘highly vulnerable populations that are systemically excluded from national or international policy making forums’ [20]. Groups commonly

described as such include the homeless, drug users, sex workers, refugees, and ethnic minorities such as Roma and Irish Travellers<sup>1</sup>. Many of these groups experience severe health inequities and face significant barriers to accessing high-quality healthcare [21–24]. Consequently, members of these groups often have poorer health status than the general population and inadequate primary care coverage [23, 25–29]. This situation resonates with Tudor Hart’s inverse care law [30] - those most in need of attention by health services are often the least likely to receive that care.

There are many barriers to accessing care for marginalised groups. These include issues relating to the way the health system functions for migrants, homeless people, drug users and people living in poverty [31–36]. Patient factors such as mistrust of services and feeling unwanted have been reported for homeless people, Travellers, drug users and migrants [22, 37–41]. Other barriers seen for particular groups include legal issues for migrants and drug users [22, 42, 43], language barriers for migrants and sex workers [43–46], competing priorities for attention in the lives of homeless people [47], and accommodation issues for those living in deprivation, the homeless, Travellers, drug users and sex workers [38, 41, 48–52]. It is often noted that these barriers do not occur in isolation and that they make patients less likely to reengage with the health services. This aligns with the concept of ‘candidacy’ and the ever-fluctuating relationship between the patient and the health service [53]. Primary care can thus help reduce inequities by acting as a familiar entry point to the wider health system. For this to happen, primary care services that are easy to engage with and acceptable to people from a variety of backgrounds are required [21]. It is rare, however, for these groups to be invited to participate in the planning of primary health services.

Therefore, suitable approaches for engaging with marginalised groups in a constructive way need to be utilised to enable them to highlight their priorities for care. Richard et al. [54] suggested developing co-operative and participatory initiatives to achieve these goals. In this research we sought to do just that - using participatory methods to include the views of a variety marginalised patients on the factors influencing their access to health services. This will then inform the development of more patient centred primary care services that are tailored to their needs.

The overall aim of this participatory study was to involve members of marginalised groups in the development of local primary care services in Ireland by incorporating their views about priority areas for action. This paper reports on the levers and barriers to accessing primary care among a heterogeneous population of marginalised groups, examining a number of shared and differential experiences of accessing primary care and identified priorities for action with regard to that primary care provision.

## **6.3 Methods**

### **6.3.1 Study setting**

This research was conducted under the auspices of the Partnership for Health Equity (PHE) in Limerick City just as a new Primary Care Team was being established in a socially deprived area of the city. (See Box 6.1)

In keeping with the aims of the national Primary Care Strategy which emphasised community participation in Primary Care Teams [4], and the ethos of the PHE, the health service planners who were PHE members wanted input from marginalised groups on the development of this PCT to identify priorities for action by the team.

The rationale for the work was two-fold. First, it was based on our knowledge that marginalised groups are excluded from participatory processes of designing healthcare services despite this being enshrined in health policy (described earlier). Second, there was anecdotal evidence that members of these groups had many barriers precluding them from accessing Irish primary care services despite being entitled to this free government-provided care ‘on paper’. (See Box 6.2)

**Box 6.1: Study setting**

The **Partnership for Health Equity (PHE)** is an innovative collaboration which engages medical educators, researchers, clinicians and health service planners from across Ireland in collaboration to work on projects seeking to improve healthcare for marginalised groups. The current partners are the University of Limerick Graduate Entry Medical School, the North Dublin City General Practice Training programme and the Health Service Executive (HSE) Social Inclusion Division. The aim of the partnership is to improve healthcare for marginalised groups by conducting relevant research, by educating future healthcare professionals and by directly providing primary care to marginalised groups. A key feature of the PHE is that research is planned with all partners and research

findings are used to inform the development of services, with a focus on priorities for action by the HSE – thereby making real differences in the day-to-day healthcare experiences of patients from marginalised groups across the country.

**Limerick City** was recognised as the most deprived local authority area in the country in 2014, with 28% unemployment and above average rates for all major causes of mortality (cardiovascular and respiratory disease, cancer, injury) [55]. Groups identified as ‘marginalised’ by the PHE in this setting included migrants, homeless, Irish Travellers, young mothers living in deprived areas, sex workers and drug users.

The **Primary Care Team** of interest was being established by the HSE and local General Practitioners (GPs) in one of the most deprived areas in the city, with a number of homeless hostels and a high migrant population. The PCT was to consist primarily of a physiotherapist, an occupational therapist, public health nurse (PHN), GPs and allied health professionals.

### **Box 6.2: Irish primary care context**

To access primary care in Ireland a patient must attend a GP and, if required, be referred to relevant members of the PCT. Patients are required to pay out of pocket to see the GP (cost up to €60 per visit) unless they have a **medical card**.

Applications for this medical card are means tested and the onus is on the patient to find a GP to sign the application form, thereby agreeing to provide care for that patient and to add them to their patient list. This implies that accessing healthcare

in the community for low income patients is dependent mainly on a GP accepting a patient's application. Patients who have been unable to find a GP can apply to the HSE to be assigned to a GP. This medical card covers the cost of visiting the GP and most of the cost of prescription medications. Certain homeless services have access to an 'emergency medical card' which allows staff to procure medical care for clients in urgent situations. When a patient with a medical card requires investigations or consultant clinics in public hospitals, there is usually a long waiting time [56]. Patients who pay out of pocket or who have health insurance will often have these appointments arranged much more quickly; this is commonly known as the **two-tier health system** (for further details see [21]). Government spending on health in Ireland, and other European countries, was reduced during the recession. As O'Donnell et al. [21] have reported in relation to migrant health services, in times of austerity, cuts are often made to services targeted at marginalised groups. In 2010 the government in Ireland introduced a '**prescription charge**' on all medications dispensed from pharmacies to patients with a medical card as a way of saving money in the health service. This levy is currently set at €2.50 per item that the pharmacist must collect on dispensing; i.e. if a patient is prescribed four separate medications for a month they must pay €10 ( $€2.50 \times 4$ ) to the pharmacist. This is an example of an out of pocket payment that seems to disproportionately affect marginalised groups.

### 6.3.2 Research design

This qualitative research was conducted adhering to the interpretive paradigm, and the study design was informed by the principles of Participatory Learning and Action (PLA) research [57, 58]. This methodology came from the work of Chambers [59] in

developing country rural settings, and has since been adapted and used for urban based primary care projects [57, 58, 60].

PLA is founded on the principles of “democracy, equity, liberation and life-enhancement” [61]. These PLA principles allow groups of participants with varying literacy levels to work together to record and discuss issues relevant to the research question posed [62]. They recognise that participants are experts on their own life experience and they are particularly useful for groups that are typically disenfranchised from involvement in research; for example, migrants and people with aphasia [63, 64]. The participants adopt the role of co-researchers contributing to data generation and analysis. Ethical approval for this study was granted by the Irish College of General Practitioners Research Ethics Committee and the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were followed for reporting of the completed work [65].

### **6.3.3 Sampling and recruitment**

Following the principles of purposeful sampling [66], the sample was drawn from six marginalised groups: migrants, homeless people, Irish Travellers, drug users, sex workers and young mothers from deprived areas of the city. Participants from these marginalised groups were contacted through gatekeeper organisations known to them or through local HSE PCT members [67]. It is not known how many participants were initially contacted by the gatekeepers, and so it is not possible to identify how many of those contacted agreed to participate in this research. This was in keeping with the ethical approval granted to the research team. The gatekeepers

also supported the research team by providing a meeting space familiar to participants for the conduct of the research sessions. All fieldwork took place in community and HSE venues in Limerick City. Shopping vouchers were offered to participants for their time at each research session. Participation in this research was entirely voluntary and a consent form was signed before the first research session. Assistance was given to those with poor literacy at every stage of the consent process.

#### **6.3.4 Research team**

This research was carried out by a multidisciplinary team of three members: two experienced PLA experts (AMacF, a female sociologist and academic who has a PhD; ET, a female research psychologist who has an MA) and one clinician who is experienced in working with marginalised groups (POD, who is a male GP). POD was known to some participants from his clinical work, but he engaged in frequent discussion and reflection on his positionality during this research. It was made clear to participants that POD was at the research sessions in his capacity as a researcher and not as a GP. ET and POD carried out the field work with the support of three GP trainees who took notes for some research sessions. A review of the research question took place with gatekeepers, and piloting of the research question and methods took place with a group of GP trainees prior to starting the formal research. The research team had regular meetings throughout the project to discuss planning issues, engagement with gatekeepers, data analysis and reporting. Updates on the research were provided to the PHE on a regular basis and findings were presented to key stakeholders in the HSE.

### 6.3.5 Data co-generation and co-analysis

The fieldwork for this study took place from July 2014 to August 2015. Data were generated by conducting focus groups [68] with four of the six marginalised groups: migrants, homeless people, Travellers, and young mothers living in areas of deprivation. Gatekeepers then advised the research team that individual interviews would be more appropriate for more vulnerable participants from the remaining two groups: sex workers and drug users. This necessitated further discussion with the research ethics committee, and approval for this modification was subsequently granted.

Three PLA techniques were used for the focus groups; these were flexible brainstorming (used in focus group 1), a card sort and direct ranking (both used in focus group 2). A detailed summary of the methods used to facilitate this approach is given elsewhere [64, 69]. Table 6.1 provides a summary of each technique as it was used in this study.

**Table 6.1: PLA techniques**

|                               |  |
|-------------------------------|--|
| <b>Flexible brainstorming</b> | Fast and creative approach using materials, images and objects to generate information and ideas about accessing primary care                          |
| <b>Card sort</b>              | An exercise in organising and thematically arranging ideas generated in the flexible brainstorming   |
| <b>Direct ranking</b>         | A democratic and transparent process where each stakeholder/participant indicated their priorities or preferences for improving primary care provision |

These techniques for generating and analysing data are highly interactive and visual. Participants can record key thoughts on the PLA charts using a variety of materials and these methods are suitable for participants with low literacy levels. Researchers work in collaboration with research participants throughout (see Figure 6.1).



**Figure 6.1: PLA chart after flexible brainstorming**

The PLA interviews with sex workers and drug users ( $n = 6$ ) used the same methodological approach, but PLA charts were not used. Additional file 1 contains the topic guides for the focus groups and interviews (See Appendix 9). All research sessions were digitally recorded and field notes and debriefing documents were prepared after each session.

### **6.3.6 Thematic analysis**

A professional transcription service was employed to produce transcripts of all recordings from the fieldwork. All transcripts and PLA charts were then thematically analysed for overarching themes relating to possible levers and barriers to accessing

primary healthcare [70]. Steps for thematic analysis described by Braun and Clarke were broadly followed [71] – including hosting data analysis sessions where all transcripts and PLA charts were displayed allowing immersion in the data, combing the data for themes, then reviewing and refining these themes and using white boards to display their development. Data from the first four marginalised groups were analysed initially and then data from interviews with participants from the two remaining groups were mapped on to these themes to provide a more complete and nuanced description of emergent themes within the data [71]. This reflects the iterative nature of qualitative data analysis; the interview data were used to confirm and validate themes (or not) developed from the focus groups. Taken together, this augmented our understanding of the experiences of accessing primary care across a range of marginalised groups. An audit trail of all theme and subtheme arrangements was maintained so that the steps in the analysis were available for scrutiny [72, 73].

### **6.3.7 Trustworthiness**

An opportunity for all participants to review their contributions as a member checking exercise was offered [74]. For three of the four groups, this took place as a separate meeting where the PLA charts and summary documents were presented to them. None of the interviewees wished to avail of the chance to review their transcripts. There the original PLA charts and a summary document were presented back to the participants. Any modifications or suggestions for changes to the reports were noted by the researchers and consensus was reached by participants on the findings. Recommendations made by the participants at these member checking meetings were incorporated into the data taken for further thematic analysis by the researchers. It is notable that the participants were encouraged to seek ‘shadowed

data' in the form of the opinions of their friends and families on the issues being discussed, and to bring these ideas back to the research sessions [75]. The core research team met regularly to discuss the work, with research notes, transcripts and reflective debriefing notes being circulated and discussed. Designated research data analysis sessions took place to discuss emerging findings across the six marginalised groups.

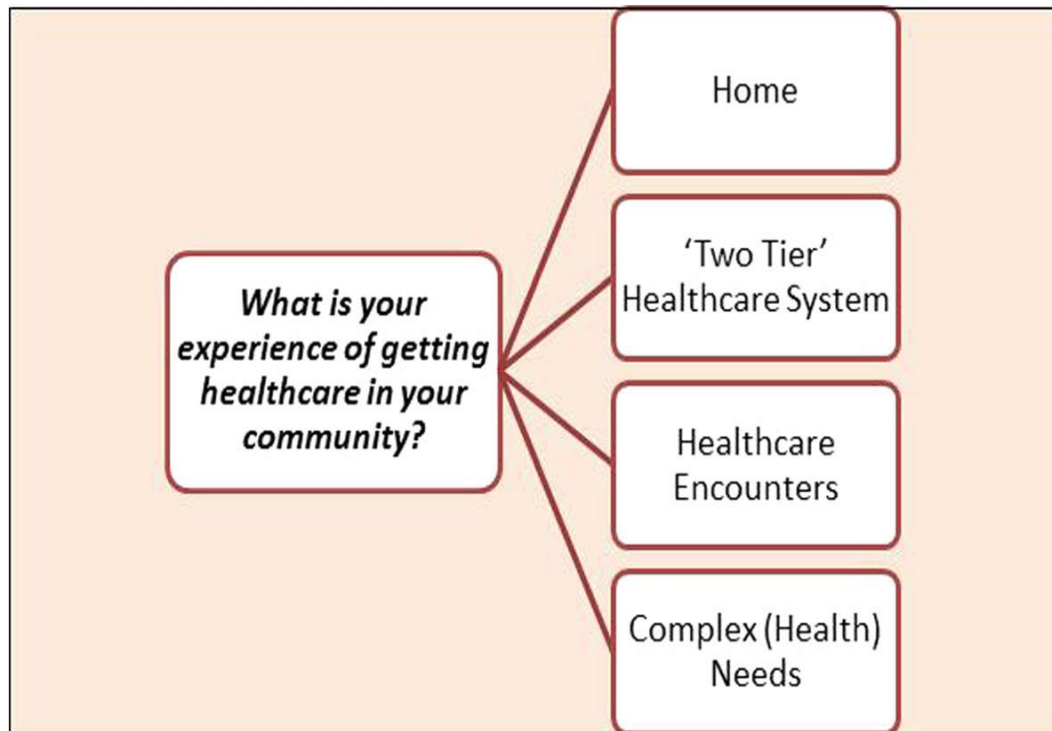
#### **6.4 Results**

A total of 21 participants were recruited across the six marginalised groups involved. Twelve focus group sessions and six interviews were conducted. Participants ranged in age from 19 to 51 years, with an average age of 31 years. Fifteen participants were female and the remaining six were male. Table 6.2 describes the breakdown of these participants by marginalised group as well as the method of data collection used. The average length of the focus group sessions was 73 minutes (ranging from 40 to 117 minutes) and the average length of the semi-structured interviews was 23 minutes (ranging from 12 to 34 minutes).

**Table 6.2: Overview of marginalised group participants**

| <b>Participant group</b>          | <b>Number of participants</b> | <b>PLA session type</b> | <b>No. of participants who attended more than one PLA session</b> |
|-----------------------------------|-------------------------------|-------------------------|---|
| <b>Migrants</b>                   | 3                             | 3 × focus groups        | 2   |
| <b>Homeless people</b>            | 6                             | 3 × focus groups        | 2   |
| <b>Traveller health advocates</b> | 2                             | 3 × focus groups        | 2   |
| <b>Drug users</b>                 | 3                             | 1 × interview           | n/a   |
| <b>Sex workers</b>                | 3                             | 1 × interview           | n/a   |
| <b>Young mothers</b>              | 4                             | 3 × focus groups        | 4   |
| <b>Gender: Female</b>             | 15                            |                         |   |
| <b>Male</b>                       | 6                             |                         |   |
| <b>Age average</b>                | 31 years                      |                         |   |
| <b>Range</b>                      | 19–51 years                   |                         |   |

Four major themes emerged from the focus groups and interviews: the home environment, the two-tier healthcare system, healthcare encounters and complex health needs (see Figure 6.2).



**Figure 6.2: Overview of themes**

These themes are described below, with an emphasis on shared and differential experiences across the groups of access to primary care and their identified priorities for improving primary care provision. Quotes are drawn from two sources: PLA session transcripts (T) or data recorded in written form on PLA charts (C).

#### **6.4.1 Home**

Home was identified as a major theme for three of the marginalised groups included in the research – homeless people, sex workers and Travellers. Data in this theme included references to the accommodation and the general living conditions of the participants, as well as the atmosphere and supports offered to residents of these places including help to access primary healthcare. For some, particularly the

homeless and sex worker groups, their accommodation in a homeless hostel often provided them with a positive and nurturing environment.

For the participants living at the homeless hostel, this was primarily a positive experience; they explained that they paid rent which covered meals and single room accommodation, but they also gained access to key worker support and a relatively stable environment. This often allowed the residents to begin reengaging with health services. Hostel staff also worked to find pathways to stable accommodation for the residents.

*'I found freedom when I came in here anyway. And then you know that they [staff] are trying to help you like, you know it is very positive.'* Homeless participant 1 (T)

Residents also provided major support to each other, with one resident describing the environment as 'one big family here' [Homeless participant 1 (C)]. Many were struggling with addiction and mental illness and they found that peer support with practical issues was invaluable. These issues included making and attending appointments, obtaining medications from pharmacy and even taking prescribed medications regularly.

In stark contrast, the Traveller participants explained feeling that their accommodation on halting sites had a negative effect on the health of inhabitants. They described health problems they felt were due to dampness, poor sanitation and

infestations. There was a sense of frustration with the municipal authorities around lack of progress in addressing these issues. Many of the sites were surrounded by high walls; as one participant explained:

*'You're locked in. It's like prison ... And if you wanna know, people are suffering seriously with their mental health over it, because depression ... no self-confidence, not being able to speak out, because they think they can't be heard ... We had protests and signs up on the wall, [we have] called the Berlin Wall ... It's very wrong.'* Traveller participant 1 (T)

As a result, Traveller participants described a feeling of being cut off from the local community and the services available, and they questioned whether the authorities were purposely hiding them from the rest of society on these halting sites. They noted that the mental health of residents suffered and stigma was increased due to these living conditions.

In identifying priorities for action, stable accommodation of a certain standard was the key priority for the Traveller participants; they felt that this needed to be addressed before any other health challenges could be looked at. The homeless participants and sex workers also felt the stability they experienced by having reliable accommodation was a priority for them.

#### 6.4.2 ‘Two-Tier’ Healthcare System

This theme was concerned with the difficulties created by the structure of the primary care system itself and the confusion around entitlements that can act as a barrier to care. The nature of the ‘opt-in’ system for publicly funded healthcare leaves many marginalised groups at a disadvantage. The obstacles described are perceived to act as a disincentive against engagement by these groups with needs.

Participants across all six groups explained that often the structure of primary care services made it difficult to engage with and access them. One man summarised his thoughts on accessing the public health system by saying: *‘I think [accessing] healthcare should be as easy as making a cup of tea!! But it’s not’* [Homeless participant 4 (C)]. Another participant wrote *‘Access to the information (chaos!)’* [Migrant participant 1 (C)] when describing the difficulty they had finding relevant information on appropriate services and entitlements. Across the groups there was resentment of the level of access and quality of care on offer to patients who could afford private care:

*‘The wealthy get more, [and] get better time from the doctors than people who haven’t got the money for it.’* Homeless participant 1 (T)

Another participant commented that for easy access to healthcare; *‘it’s all about the money! [you pay]’* [Young mother 2 (C)], and that *‘doctors should treat everybody equally’* [Young mother 2 (C)] whether they were private patients or not.

Difficulty in accessing primary healthcare as a public patient was also discussed by participants; finding a GP to accept them for care was an aspect of the system that posed particular problems for the homeless and drug using groups. Participants perceived this as discrimination. One participant described his attempt to enrol at a GP clinic:

*'They told me come out [to the clinic], they told me they had space, they told they'd take me on. I went out there, the doctor had a look [at me], said something to the secretary, he went away, the secretary called me, "he's just after letting me know there he's full" [and will not accept you as a patient]. Now I found that with a few [doctors], just not him, that when they saw me ... that they didn't want to know [take me on].' Drug using participant 1 (T)*

As described in Box 6.2 in the methods section, to apply for access to the primary care system in Ireland you must complete specific forms and submit documentation. This process was noted to be difficult for many participants across the homeless, drug user and sex worker groups and they often did not complete the process of applying, often leaving them without access to healthcare in the community. One participant explained what this situation meant for her:

*'I have no medical card ... because it went out of date being inside [prison] and I just didn't get renewed ... I need it like; I*

*need to get my teeth fixed and keep an eye on the fucking Hep C, and ... when I do come off the stuff [heroin] myself ... it won't be too bad after that.'* Sex working participant 1 (T)

Participants across four of the groups (sex workers, drug users, homeless and young mothers) felt the prescription levy on medication prescribed by the GP was a big problem. One homeless participant called the charge a 'ransom' [Homeless participant 1 (C)], and another explained: *'I really think the €2.50 prescription charge is a real threat to life, I have watched people choose which meds [medications] to take home'* [Homeless participant 4 (C)]. Others revealed that they had not commenced contraception and treatment for infections as they could not pay this charge. Many marginalised patients found this cost forced them to choose between medications and other important expenses:

*'People ... they're getting their dole [weekly welfare payment] ... and [out of that money] you're getting your shopping, you're paying your electricity bills and then, and if they're on a lot of medications [this levy is] costing fifteen euro. Like their electricity or their life [medications], do you know what I mean? ... they might say oh I'll get my medication during next week and I'll get my electricity now. But they're putting their life in danger then.'* Drug using participant 2 (T)

Many participants reported that they traditionally relied on community pharmacists for health advice, but for some this relationship has suffered greatly since this

prescription charge was introduced as they avoided going to certain pharmacies where they owed money for this levy.

Participants from the young mothers group also mentioned appointment systems in community clinics, particularly in GP clinics, as a barrier to care. They made suggestions for changes that could be made to the eligibility criteria for certain community health services; these factors were identified as priorities for action by this group. Strict referral criteria prevented one participant's mother from accessing a free chiropodist in the community; she was not old enough to qualify for the service even though she had many chronic illnesses.

The migrant group felt strongly that knowledge concerning the availability of and entitlement to primary care services was a key factor in being healthy and staying well. This was identified as one of their priorities for action in relation to accessing primary care. The rights of patients in relation to making complaints, changing GP, checking qualifications of healthcare providers and requesting information on their own care were noted to be of particular interest:

*'I think you need to write [information] in black and white; like how do you do it, ABC, because it's like survival thing.'* Migrant participant 1 (T)

### 6.4.3 Healthcare encounters

This theme includes face-to-face encounters in clinical settings and the experiences of marginalised people in these settings. Past experiences of participants and members of their social networks when engaging with the healthcare system and providers in the community formed an important theme across all groups in the research. Three of the marginalised groups (young mothers, Travellers and migrants) reported having contact with a wide array of healthcare professionals in the community, while others in more vulnerable and disorganised situations often reported less frequent encounters.

Many participants from the groups (migrants, young mothers, drug users and homeless) were adamant that individual healthcare professionals had engaged with them and helped them greatly. One explained about her GP:

*'She's worried more about me than I worry about myself!' Young mother 3 (T)*

Others explained that continuity of care was ideal and seemed to be conducive to attending for care in the community when required. Making access to healthcare professionals as easy as possible was highlighted; the young mothers described a programme where speech and language therapists attended the local crèche to screen for problems. They remarked that this was a big change from the usual system where patients had to try to navigate access to these services by themselves. Others mentioned social workers and pharmacists who had helped them with problems

related to their health. Overall, it was the attitudes of the staff that seemed to make people feel welcome and more likely to engage. One participant explained her relationship with a public health nurse:

*'I think she's marvellous ... her attitude is good towards people ... even if she's in a rush she'd still look after you ... It makes it different because she talks to you, she doesn't make you feel that you're belittled [not important], you know what I mean? Some people make you feel that they're over you [more important than you]; because they're a doctor or nurse ... you should bow down to him. It's not like that down there [PHN clinic], it's like you're the same.'* Drug using participant 2 (T)

Participants from the migrant group were eager to contrast their engagement with primary care in Ireland to their countries of origin. Some felt that the documenting of full informed consent before any procedure or intervention was very common in the Irish setting. This approach was not always employed for medical interventions in their home country, even for small things such as vaccination, and they found it a positive change that they preferred. Participants also explained that during prior primary care visits they were often subjected to large numbers of tests and investigations for health problems in their home countries, and this contrasted with the *'relaxed attitude'* [Migrant participant 1 (C)] of the wait-and-see approach employed by many GPs in Ireland.

On the other hand, all participant groups also described negative experiences and encounters with healthcare services and professionals in the community. Poor communication, particularly by GPs, was noted by participants across many of the marginalised groups. This left patients feeling dissatisfied and lacking confidence in the care provided to them. One said of her GP:

*'He just look into his [computer] system and just prescribe medication for me.'* Migrant participant 2 (T)

This feeling was echoed by others who noted that GPs often wanted very brief consultations, and even then they were not listening to the health problems being explained to them. This was described as:

*'A conveyer belt; just in one door and out the other ... get your prescription and of out the door with you.'* Homeless participant 2 (T)

These actions were understood to imply that the doctors were not interested in the problems being presented by these patients. Communication difficulties were magnified for the migrant group, where language problems seemed to increase the frustration felt during consultations. None of these participants noted being offered the services of an interpreter in a primary care setting. Having one present would likely have facilitated better communication during consultations, and avoided this situation:

*'They [patients] will feel so ignored because they can't speak English.'* Migrant participant 2 (T)

However, some of these same participants were sympathetic to healthcare providers and their difficulties with the language barriers:

*'It's hard for the patient and GP as well. He doesn't understand what is the person talking about. So maybe doesn't understand the problem. So he gives maybe the wrong medicine.'* Migrant participant 3 (T)

Even with a shared language, the words and phrases used in primary care consultations were noted to be important by the Traveller participants also, as they could easily be misunderstood or misinterpreted. They mentioned that many people had poor understanding of basic health concepts and that often doctors didn't acknowledge this and take the time to explain illnesses or medications to them. This use of complex medical language could be seen to act as a barrier to accessing care:

*'When people go to the doctors, [they need] to explain better the big formal words that they uses ... [they are] too complicated for people, especially older people ... All these fancy [medical] words that they don't have a clue, unless, if there was one of us sitting with him then fine, but if he [her father] goes in on his own, you might as well be sending a two year old child in [to the doctor].'* Traveller participant 2 (T)

Unsurprisingly therefore, the need for clear communication tailored to the needs of the patient presenting to primary care was mentioned as a priority for action by the Traveller and migrant groups.

Participants in the homeless and drug using groups who were on opioid replacement therapy (methadone) reported that often when they attended GPs, the focus was on the methadone only and other health concerns were ignored. Also, local pharmacies serve as sites for needle exchange for drug users. One participant recounted that her friend had been asked by a pharmacist what needles she required in front of other customers and this left her feeling:

*'Ashamed, coming out red faced, looking to see did anyone see you, mortification, do you know what I mean. It's just, it's wrong.'* Drug using participant 2 (T)

These apparent breaches of confidentiality by staff had stopped her and others from going to certain pharmacies for any health reason. Many of these adverse experiences were described by participants across the groups, and seemed likely to deter them and people in their networks from attending for healthcare appointments in the community. One homeless participant summarised this sentiment well when he said about his GP:

*'He's not a man to listen, that's what I put it down to; that's why I don't bother contacting him.'* Homeless participant 2 (T)

When focusing on priorities and ways to improve these healthcare encounters, many participants across all groups felt that this would be difficult if healthcare providers did not understand the complexity of problems faced on a daily basis by patients from the marginalised groups. One participant said:

*'It makes me sad that you have to constantly keep explaining yourself and trying to get people to understand your side of it and where you're coming from, and what's behind you, and what's in front of you, and the barriers that's around.'* Traveller participant 1 (T)

Without a true understanding of the 'lived experience' of these patients, it can be difficult for professionals to improve their access to primary care, and ultimately their health. The view that those working in primary care needed to try extremely hard to understand the difficult lives of these patients was a priority for all participant groups. Another participant explained the huge social distance between the providers and marginalised patients can make engagement and collaboration around health very hard:

*'Girls that are on the street [sex] working, they'd rather talk to another girl that is working than go and talk to a complete stranger, or a doctor about something that they might have wrong with them ... Yeah it's like, you [the doctor] haven't clue what I've been through.'* Sex working participant 2 (T)

Participants from the migrant group also felt that there needed to be mutual respect for culture in every healthcare interaction and this was suggested as a topic for healthcare professional education; this was therefore a priority for them. Others suggested providers should learn about communication and empathy with marginalised groups:

*'I think they should talk to ... the nurses and doctors and tell them when they're seeing their patients not to be so abrupt with them ... when they see their patients; just seeing them as a person and not as a disease ... That [patient] person is a person like the doctor, they have feelings, they have to be treated as a human being ... For instance, over being on the gear [heroin], I'm frightened to go out to the hospital and down to [the GP to] tell them I'm on the gear; because the attitude [of staff] will change.'*

*Drug using participant 2 (T)*

#### **6.4.4 Complex (health) needs**

This theme concerns a variety of physical, mental and emotional health issues pertaining to the social determinants of health. Mental health problems were described across almost all of the groups (young mothers, drug users, Travellers and homeless) and many participants spoke of the experiences of their friends and families.

Feelings of stress and anxiety were described by participants in all except the migrant group. Of those with anxiety, many were on prescribed treatments for this, while others explained that they self-medicated with street drugs. This condition impacted on the daily lives of people to such a degree that it made them feel dehumanised; like they were going through the motions of daily life without actually participating in it:

*'I feel that as well – I feel I exist, I don't feel I'm living my life.'*

*Homeless participant 3 (T)*

Depression and self-harm were frequently mentioned, with attempts at suicide being described as a common occurrence:

*'A lot of people jumped into the river ... [it's now] just everyday*

*kind of thing ... It's like a new craze or something.'* Young

*mother 3 (T)*

Improving community mental health services for dealing with people in crisis was specifically suggested by members of the young mothers group as a priority for primary care services. One participant mentioned possible actions:

*'Suicide is a big issue; there should be billboards or more*

*advertising about places [to go for help] ... There should be*

*centres for suicide ... like for people who are thinking about it, or*

*have thoughts. And they should have more solutions and more*

*funding.'* Young mother 2 (T)

Some participants from the young mothers group were critical of the ways in which mental health issues, particularly anxiety and depression, were dealt with in primary care. Mental health problems and their management were in fact priorities for the Traveller, homeless, young mothers, drug users and sex worker groups. The young mothers group went further, to recommend certain ways to improve knowledge about community mental health services, and improve their accessibility. They were particularly worried about over-prescribing of anti-depressants and the lack of discussion around alternative treatments for mental health issues, such as relaxation or psychological interventions.

Addiction and the '*vicious circle*' [Homeless participant 3 (C)] that it can create were documented as being a cause of ill health, but also the associated lifestyle can create barriers to improving health. Living under threat of violence and worries about legal problems were often part and parcel of this existence. The physical effects of drugs and their withdrawal symptoms were described as direct barriers to accessing care in the community. One participant described how her addiction affected her ability to follow medical advice having seen a GP:

*'The script [prescription] could be still thrown in there [indicating to her bag] two or three weeks later and I wouldn't have bothered with it ... [with] addiction you just, you know what I mean, fuck it, couldn't give a shit, too busy taking drugs and trying to think of getting money [for drugs], you know?'* Sex working participant 1 (T)

Discrimination and prejudice experienced by some participants led to feelings of isolation from the rest of society, and this in turn contributed to poor mental health. Anger and despondency were the emotions some participants described when faced with these prejudices. Some participants experienced multiple challenges and forms of marginalisation, as this quote from a participant who was drug using and also sex working shows:

*'I'm on heroin, and I've been struggling with that since I'm fourteen, so I've been dealing with things on the street [sex working] then as well, which is really hard, and I got mixed up with that all through my addiction, which I'm not proud of but it's kind of ... I mean when you sit at your bed at night like you're thinking, I've all these health issues and you're kind of scared to go [for help] about them. And then when you do go about them, there's no one that actually wants to listen, that's the way you feel.'* Sex working participant 2 (T)

Participants, particularly from the Traveller group, mentioned the importance of tradition and culture in dealing with health issues. Tradition can complicate both the seeking of care in the community and the solutions to health problems that may be suggested. They explained that for their community the concept of privacy and keeping issues within the family were of the utmost importance. It was noted, however, that what was tolerated could change over time with education and

discussion. The promotion of tolerance and improved understanding of all groups in society was noted as a way to try to improve this:

*'We're all the same, we just come from different ethnic backgrounds ... we're all human at the end of the day; it doesn't make a difference whether you're black, white, pink, purple, it – we're not here to discriminate ... we've all blood running through our veins, we all have feelings, we all – we just come from different backgrounds and there is serious barriers there, between the guards, the communities, the doctors, the nurses, everybody has their own issues.'* Traveller participant 1 (T)

Solutions to these complex health problems identified by participants included finding advocates to assist them in accessing healthcare and supporting navigation of the health system. Participants from the Traveller group were themselves on a Traveller Health Advocacy training programme to improve their literacy and advocacy skills along with their basic knowledge of a range of relevant health topics. On completion, they will work to improve the health of their community, and their role is an example of an enabler to accessing primary healthcare:

*'It involves going out to the Travelling community and meeting people from all different walks of life, it's about bettering their health, giving them information that maybe they have never received ... it's about [helping] people who can't read and write and explain to them about what's on their [information] leaflets*

*... basically what we do is we deliver an awful lot of information out on to the Traveller community.’ Traveller participant 1 (T)*

Participants in the homeless, drug using and sex worker groups spoke about the support of key workers in helping them to try to understand the complexities of the primary care system. Examples of practical supports with making telephone calls, reminders for medical appointments and the provision of transport to appointments were all described in these groups. One said of the supportive relationship she had developed:

*‘I personally deal with a man called B and he's just great, he knows all about the addiction; why would you start on it [heroin] and I mean he meets me and we'd go anywhere for a cup of coffee, sit down. And I notice when you leave [the meeting] then ... it's kind of like a breath of relief you know; you say to yourself – that was really nice.’ Sex working participant 2 (T)*

Collaborating with a key worker seemed to remove some of the impediments to accessing primary care discussed previously. Other participants mentioned having transport to clinics, and attending services that offered a comprehensive approach to healthcare for their needs. One example mentioned a location where medical and harm reduction services were co-located:

*‘It's easy to get to because they [key workers] come and collect you, and bring you to A, and get you back here. Because that's a*

*big part of stopping you from getting there as well as the, is trying to get there so you know what I mean. It's easier to be picked up and brought ... so you have your [addiction] counselling or whatever, the doctor there and your one to ones [needle exchange] all in the one.' Drug using participant 2 (T)*

The roles of peer advocates and key workers serve as important facilitators to reengagement with the primary healthcare system. It is not surprising then that the homeless group, drug users, sex workers and Traveller participants all mentioned these types of support as priorities.

#### **6.4.5 Priorities**

Some of the priorities for action across the marginalised groups involved in this research have already been highlighted in the description of results. Table 6.3 provides a synthesis of the priorities identified for each group, and across groups. Some marginalised groups involved in the research recommended specific solutions, and these are also included in the table. It is clear from Table 6.3 that participants from across marginalised groups had shared views on priority areas for action.

**Table 6.3: Priorities for action across the participant groups**

| <b>Priority Issue</b>        | <b>Identified by</b>  | <b>Specific solutions suggested to address the priority</b>   |
|------------------------------|---|---|
| <b>Home</b>                  | <ul style="list-style-type: none"> <li>• Travellers</li> <li>• Homeless &amp; Sex workers</li> </ul>  | <ul style="list-style-type: none"> <li>• Need satisfactory accommodation for any effective primary care engagement to happen</li> <li>• Supports afforded by stable accommodation needed to continue</li> </ul>   |
| <b>Two-tier system</b>       | <ul style="list-style-type: none"> <li>• Young mothers</li> <li>• Migrants</li> </ul>   | <ul style="list-style-type: none"> <li>• Need for flexibility around eligibility and referral criteria for primary care services</li> <li>• Increased availability of information on entitlements and ways to engage with primary care</li> </ul>   |
| <b>Healthcare encounters</b> | <ul style="list-style-type: none"> <li>• Migrants</li> <li>• Travellers</li> <li>• Migrants &amp; Drug users</li> <li>• All groups</li> </ul> | <ul style="list-style-type: none"> <li>• Better communication in primary care, including availability of trained interpreters</li> <li>• Better communication in primary care; awareness of general literacy and health literacy of patients</li> <li>• Educating professionals on communication skills and empathy</li> <li>• Understanding adversity faced by patients</li> <li>• Show more empathy with the patient</li> </ul> |
| <b>Complex health needs</b>  | <ul style="list-style-type: none"> <li>• Young mothers</li> <li>• Travellers</li> <li>• All groups</li> </ul>                                 | <ul style="list-style-type: none"> <li>• Improved knowledge of and availability of community mental health services</li> <li>• Promotion of tolerance and awareness of prejudice</li> <li>• Supports to access primary care including engaging peer advocates or key workers; modelled on the Traveller group advocacy role</li> </ul>  |

## **6.5 Discussion**

### **6.5.1 Statement of principal findings**

This study involved 21 members of marginalised groups to investigate their views about access to primary care and to identify priorities for the development of local primary care services. It highlights four key themes in relation to access to primary care for the marginalised groups and priorities for action: the importance of the home environment, the healthcare system and how it is structured, encounters with

healthcare professionals, and the complexity of the needs of the groups taking part. Many of the identified barriers were experienced across a number of the marginalised groups and there were similarities in the identified priorities for action across groups. This project demonstrated the effective use of participatory methods for engaging with marginalised groups in a significant way that saw them defining their own needs and priorities.

### **6.5.2 Discussion of findings in relation to the literature**

The primacy of **Home** and the benefit of having secure and supportive accommodation from the state were articulated by many participants from the homeless and sex worker groups, while for the Traveller group, accommodation they were provided with had a negative effect on the health of inhabitants. This demonstrates that the home environment can act as a springboard to stability and healthcare access and allow a person to begin to address some of the issues they face, or it can contribute to their existing problems. This idea has previously been described in reports and the literature in relation to Irish Travellers, homeless people and drug users [38, 50, 51, 76, 77] and resonates with discussion of the wider social determinants of health [78]. Inter-departmental and inter-sectoral actions to prioritise the creation of stable and supportive home environments for people in the community should be a tenet of any healthcare service.

The **‘Two-Tier’ Healthcare System** that exists in Irish primary care created confusion, which acted as a barrier to care and a source of stress for individuals who were already struggling. The challenges of relying solely on publicly provided care

have been reported elsewhere [36]. Further, the finding that the imposition of an ‘out of pocket’ expense, such as the prescription levy, can act as a barrier to medication adherence resonates with the findings of Sinnott et al., who reported on publicly funded patients internationally [79]. We have seen here that this moderate co-payment was seen as a major hurdle for members of marginalised groups. These findings highlight the need for universal healthcare as called for by the World Health Organization [80, 81]. Furthermore, allowing flexibility around referral criteria and appointments for primary care services should be considered when caring for marginalised groups, as suggested by the young mothers group.

Descriptions of **Healthcare Encounters** that are perceived by the patients as poor quality are a recurring theme in the existing literature and were echoed in this study [37, 38]. Communication difficulties were magnified for the migrant group, where language problems increased the frustration felt during engagement with primary care professionals; this has been described previously by Biswas et al. [43] and Newbold et al. [45]. None of the migrant participants in this research spoke about being offered the services of an interpreter in a primary care setting. This echoes findings from O’Donnell et al. [21] and MacFarlane et al. [46] that the provision of interpretation services in Ireland is inadequate. The perceived poor attitudes of primary care professionals towards patients from marginalised groups in this study resonates with findings from many other studies on this topic [32, 33, 37–39, 41, 43, 82–84]. These adverse experiences seem to deter participants in this study from attending for primary care in the community. This finding demonstrates the many complex challenges and layers of marginalisation experienced by these groups and highlights the need for a multifaceted approach to dealing with the issues. Many

participants in this study felt that healthcare professionals needed to understand these complexities of the problems facing marginalised groups, and identified professional education in communication skills and empathy as a priority. Without a true understanding of the ‘lived experience’ of these patients, it can be difficult for professionals to improve their access to primary care, and ultimately their health. There is evidence to support Allport’s ‘contact hypothesis’ [85] in relation to these issues; this theory explains that allowing interaction between two very different groups (e.g. homeless patients and trainee GPs) in supervised settings can lead to improved understanding and changed attitudes for both parties.

**Complex (Health) Needs** were experienced by the participants across all groups. Improving community mental health services for dealing with people in crisis was identified as a priority for the young mothers in particular. Accounts of marginalised groups struggling with ‘competing priorities’ in their daily lives have been reported in the literature on homelessness and deprivation [47, 48], but in our work this concept is seen across other groups. The Traveller participants, for example, felt that living in sub-standard accommodation was the primary issue for them to resolve before they could look at enhancing their engagement with primary care services. Others described poor literacy and the subsequent inability to complete applications or understand medication instructions as important problems in relation to their health. These are concrete examples of the social determinants of health in action and highlight that the enhancement of health often requires intensive work on a much broader array of social factors [78]. Being trapped in a cycle of addiction has been reported as a barrier to primary care [41, 77]. This ‘vicious circle’ of addiction

compounds the problem of engagement, and primary care professionals need to be aware of these complexities.

Solidarity among members of most of the groups was notable, and reliance on peers who understand the common adversity faced was an important facilitator to navigating primary care access for many. In terms of facilitating healthcare change, some participants described initiatives and agents already working in their communities to try to facilitate effective engagement with primary care. Participants identified advocates who tried to assist them in accessing healthcare and supporting navigation of the health system. Engaging with key workers and peer advocates seemed to reduce some of the obstacles to accessing primary care and facilitate reengagement. Participants from the Traveller group were themselves on a training programme to improve their literacy and advocacy skills along with their basic knowledge of a range of relevant health topics. This model is an example of an enabler to accessing primary healthcare which could be adapted for implementation across other marginalised groups.

While our research focused on interactions with any members of multidisciplinary PCTs, most participants spoke only of meeting GPs, public health nurses or pharmacists. Widening the array of professional support available to marginalised groups can enhance and support health promotion and prevention models of healthcare facilitated by such individuals.

### **6.5.3 Strengths and weaknesses of the study**

This is one of the first studies to include the voices of a variety of marginalised groups in exploring barriers and facilitators to primary care access with the intention of using these findings to direct action in primary care structures. Various strategies were employed to ensure the rigour of the work, including triangulation, member checking, reflexivity, peer debriefing and reaching data saturation [61, 74]. The collaboration with gatekeeper organisations allowed engagement with some groups traditionally considered ‘hard to reach’ [67]. Participatory methods for working with research participants with varying literacy levels were well received by those taking part. Participants introduced ‘shadowed data’ from their friends and families into the discussions and ideas for the PLA charts; this widened the representation of the marginalised groups [75].

There are also some study limitations. The overall sample size is modest and the sample size for individual marginalised groups is small. The sample is also from one urban setting only. This does limit the range of experience being offered for analysis and used to identify priorities and, as with all qualitative studies, raises questions about the credibility and transferability of findings. However, the overall sample of 21 and the repeated engagement of several participants are positive given the complex and chaotic lives being lived. Also, the resonance of key findings with previous literature (described earlier) suggests that the findings have authenticity and relevance for service planning.

The PLA methods used with the focus groups ideally require repeated meetings over a period of time, thereby allowing participants to reflect and discuss the research with others in their networks. Arranging the schedules of research was difficult in some cases due to the chaotic lives of some of the participants; crises including the sudden death of one participant between meetings meant adaptations had to be made. Despite maximal flexibility of the research team and the gatekeepers it was not possible to have the same participants present at all research sessions. Finally, all participants in this research were clients of gatekeeper organisations and so had some history of contact and engagement in an effort to improve their lives. They may therefore be seen as having more knowledge and resources to access primary care than other members of the same marginalised groups who are not working with gatekeepers.

#### **6.5.4 Clinical and policy implications**

The findings from this study have a number of clinical implications. Ineffective styles of communication used by healthcare practitioners were highlighted as a barrier to healthcare access, and so the education of these front-line professionals and their support staff on relevant skills should be prioritised. Making appropriately qualified interpreters available to patients who require support with language in all primary care settings is another recommendation on the issue of communication.

Widening the access for marginalised groups to other members of the PCT beyond GPs and PHNs should be considered, as well as flexibility around referral and eligibility criteria for accessing certain primary care services. Key worker

organisations and advocacy programmes should be resourced to allow them to work to facilitate the navigation of primary care by members of marginalised groups.

Government levies such as the ‘prescription charge’ seem to disproportionately affect the marginalised groups we researched, and exemptions should be considered for these groups. The HSE Social Inclusion Division was instrumental in recently securing an exemption for asylum seekers from paying prescription charges.

Simplifying the system of application for and retention of medical cards would also help many vulnerable patients to engage with primary care [86]. Removing the link between being granted a medical card and finding a GP to accept you as a patient would allow many members of marginalised groups a certain degree of access to primary care. Lastly, attempting to address basic needs such as education and housing is important for all of society, but particularly in relation to the health of marginalised groups.

### **6.5.5 Areas for further research**

It would be valuable to analyse marginalised groups’ experiences of participatory learning and action research methods and to explore how they experience them compared with other research studies that they may have been involved in. It would also be interesting to use PLA to work with marginalised groups to explore their experiences and priorities in relation to secondary care and access to aspects of social care. The cost effectiveness of designing interventions that address a priority issue for a number of marginalised groups should be evaluated. For example, healthcare professional education on communication skills and competencies for

working with a wide variety of marginalised groups could be developed and evaluated from this perspective. Innovative ways of improving access to primary care services for marginalised groups, such as peer support networks, should be explored and evaluated.

## **6.6 Conclusions**

There are many complicated personal and structural barriers to healthcare access shared across a number of marginalised groups. They also have shared views on priority areas for action. If steps are taken to address these priorities, there is scope to impact on more than one marginalised group and to address the existing health inequities.

## **6.7 List of abbreviations**

|       |  |
|-------|--|
| PPI   | Patient and Public Involvement                           |
| PLA   | Participatory Learning and Action                        |
| PHE   | Partnership for Health Equity                            |
| PCT   | Primary Care Team  |
| GP    | General Practitioner                                     |
| HSE   | Health Service Executive                                 |
| COREQ | Consolidated Criteria for Reporting Qualitative Research |
| PHN   | Public Health Nurse                                      |

## **6.8 Declarations**

### **6.8.1 Ethics approval and consent to participate**

Ethical approval for this research was granted by the Irish College of General Practitioners Research Ethics Committee. Informed consent was gained from all participants at each research session. To protect participants' identity and ensure confidentiality, the gatekeepers have not been named.

### **6.8.2 Consent for publication**

Not applicable.

### **6.8.3 Availability of data and material**

The datasets generated and/or analysed during the current study are not publicly available, as analysis is ongoing for a further publication based on this dataset.

### **6.8.4 Competing interests**

None.

### **6.8.5 Funding**

Funding for this research was obtained from the Irish Health Service Executive Social Inclusion Division. DN (a listed author), representing the funder, contributed as listed below.

### **6.8.6 Authors contributions**

AMacF was principal investigator of the study, which was developed in collaboration with DN, AOC, POD and ET. POD led the ethical approval process. ET led fieldwork with the assistance of POD. All authors were involved in research meetings as work progressed. AMacF, POD and ET conducted data analysis and write-up. All authors approved the final manuscript.

### **6.9 Acknowledgements**

We would like to acknowledge that the funding for this research was provided by the HSE Social Inclusion Office. We would like to formally acknowledge the contributions of the following people to this work: all research participants and gatekeepers, Dr Fiona O'Reilly, Maurice Hoare, Dr Rose Galvin, Dr Ray O'Connor, Dr Caitriona O'Riordan, Dr Negin Reyhani and Dr Christina McDonnell.

### **6.10 Author details**

POD is a GP and Clinical Fellow in Social Inclusion at the University of Limerick Graduate Entry Medical School. ET is Senior Researcher in Primary Healthcare at the University of Limerick Graduate Entry Medical School. AOC is a GP and the Programme Director of the North Dublin City GP Training Scheme. DN is the National Lead of the Health Service Executive Social Inclusion Division. AMacF is Professor of Primary Healthcare Research at the University of Limerick Graduate

Entry Medical School. POD, AOC, DN and AMacF are all members of the Partnership for Health Equity ([www.healthequity.ie](http://www.healthequity.ie)).

### **6.11 Endnote**

<sup>1</sup>Irish Travellers are defined as ‘the community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions, including historically, a nomadic way of life on the island of Ireland’ [87].

### **6.12 Additional files**

See Additional file 1 (Appendix 9) for interviews and focus group topic guide

### **6.13 References**

1. Charles C, DeMaio S. Lay participation in health care decision making: a conceptual framework. *J Health Politics Policy & Law* 1993;18(4):881–904.
2. Health Canada. The Health Canada Policy Toolkit for Public Involvement in Decision Making. 2010. [http://www.hc-sc.gc.ca/ahc-asc/alt\\_formats/pacrb-dgapcr/pdf/public-consult/2000decision-eng.pdf](http://www.hc-sc.gc.ca/ahc-asc/alt_formats/pacrb-dgapcr/pdf/public-consult/2000decision-eng.pdf). Accessed 1 Mar 2016.
3. Department of Health. Involving patients and the public in healthcare: Response to the listening exercise. 2001. <http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.g>

[ov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4079841.pdf](http://ov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4079841.pdf). Accessed 10 Jul 2016.

4. Department of Health and Children. Primary care: a new direction. 2001.  
<http://www.dohc.ie/publications/pdf/primcare.pdf?direct=1> Accessed 01 June 2015.
5. World Health Organization. Primary care: Now more than ever. 2008.  
<http://www.who.int/whr/2008/en/>. Accessed 1 Mar 2014.
6. Neuwelt P. Community participation in primary care: What does it mean ‘in practice’? *J Primary Health Care* 2012;4(1):30–8.
7. World Health Organization Regional Office for Europe. Poverty and social exclusion in the WHO European Region: Health systems respond. 2010.  
[http://www.euro.who.int/\\_data/assets/pdf\\_file/0006/115485/E94018.pdf](http://www.euro.who.int/_data/assets/pdf_file/0006/115485/E94018.pdf). Accessed 12 Oct 2015.
8. World Health Organization and United Nations Children’s Fund. Declaration of Alma-Ata. International Conference on Primary Health Care. Alma-Ata, USSR: World Health Organization; 1978.
9. Draper AK, Hewitt G, Rifkin S. Chasing the dragon: Developing indicators for the assessment of community participation in health programmes. *Social Sci & Med* 2010;71(6):1102–9.
10. Morgan LM. Community participation in health: Perpetual allure, persistent challenge. *Health Policy & Planning* 2001;16(3):221–30.

11. Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite, J. Implementing strategies in consumer and community engagement in health care: Results of a large-scale, scoping meta-review. *BMC Health Services Res* 2014;14(1):1.
12. World Health Organization. WHO global strategy on people-centred and integrated health services: Interim report. *Service Delivery and Safety* 2015. [http://apps.who.int/iris/bitstream/10665/155002/1/WHO\\_HIS\\_SDS\\_2015.6\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/155002/1/WHO_HIS_SDS_2015.6_eng.pdf). Accessed 10 Feb 2016.
13. Assai M, Siddiqi S, Watts S. Tackling social determinants of health through community based initiatives. *Br Med J* 2006;333(7573):854–6.
14. National Institute for Health and Care Excellence. *Community engagement: Improving health and wellbeing and reducing health inequalities*. 2016. <https://www.nice.org.uk/guidance/ng44/resources/community-engagement-improving-health-and-wellbeing-and-reducing-health-inequalities-1837452829381>. Accessed 1 Jul 2016.
15. Tempfer BC, Nowak P. Consumer participation and organizational development in health care: a systematic review. *Wiener Klin Wochenschr* 2011;123(13):408–14.
16. Ramsden VR, McKay S, Crowe J. The pursuit of excellence: Engaging the community in participatory health research. *Glob Health Promot* 2010;17(4):32–42.
17. Kegler MC, Norton BL, Aronson RE. Strengthening community leadership: Evaluation findings from the California Healthy Cities and Communities program. *Health Promot Pract* 2008;9(2):170–9.

18. Gaventa J, Barrett G. Mapping the outcomes of citizen engagement. *World Dev* 2012;40(12):2399–410.
19. Schiffer K, Schatz E. Marginalisation, social inclusion and health. Amsterdam: Foundation Regenboog AMOC & Correlation Network. 2008. <http://www.correlationnet.org/images/stories/pdfs/products/marginalisation.pdf>. Accessed 1 Jan 2016.
20. Siddiqui FR. Annotated bibliography on participatory consultations to help aid the inclusion of marginalized perspectives in setting policy agendas. *Int J Equity Health* 2014;13(1):1.
21. O'Donnell CA, Burns N, Mair FS, Dowrick C, Clissmann C, van den Muijsenbergh M, et al. Reducing the health care burden for marginalised migrants: the potential role for primary care in Europe. *Health Policy* 2016;120(5):495–508.
22. Islam MM, Topp L, Day CA, Dawson A. The accessibility, acceptability, health impact and cost implications of primary healthcare outlets that target injecting drug users: a narrative synthesis of literature. *Int J Drug Policy* 2012;23(2):94–102.
23. All Ireland Traveller Health Study Team. All Ireland Traveller Health Study: Our Geels – Summary of findings. School of Public Health, Physiotherapy and Population Science, University College Dublin. 2010. [https://www.ucd.ie/t4cms/AITHS\\_SUMMARY.pdf](https://www.ucd.ie/t4cms/AITHS_SUMMARY.pdf). Accessed 1 Feb 2016.
24. Dixon-Woods M, Agarwal S, Kirk D. Vulnerable groups and access to health care: a critical interpretive review. National Co-ordinating Centre for NHS

Service Delivery and Organisation. 2005.

[http://www.netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1210-025\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1210-025_V01.pdf).

Accessed 27 Jul 2016.

25. Story A. Slopes and cliffs in health inequalities: comparative morbidity of housed and homeless people. *Lancet* 2013;382:S93.
26. O'Reilly F, Barror S, Hannigan A, Scriver S, Ruane L, MacFarlane A, et al. Homelessness: an unhealthy state – Health status, risk behaviours and service utilisation among homeless people in two Irish cities. *Partnership for Health Equity*. 2015.  
[http://media.wix.com/ugd/b6d55d\\_ace6c285c5c5414e94eeb1bf11ca82f9.pdf](http://media.wix.com/ugd/b6d55d_ace6c285c5c5414e94eeb1bf11ca82f9.pdf).  
Accessed 1 Nov 2015.
27. Balfour R, Allen J. A review of the literature on sex workers and social exclusion. Institute of Health Equity University College London. 2014.  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/303927/A\\_Review\\_of\\_the\\_Literature\\_on\\_sex\\_workers\\_and\\_social\\_exclusion.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/303927/A_Review_of_the_Literature_on_sex_workers_and_social_exclusion.pdf). Accessed 11 Nov 2015.
28. Dias S, Gama A, Cortes M, de Sousa B. Healthcare-seeking patterns among immigrants in Portugal. *Health Soc Care Commun* 2011;19(5):514–21.
29. Schoevers MA, Loeffen MJ, van den Muijsenbergh ME, Lagro-Janssen AL. Health care utilisation and problems in accessing health care of female undocumented immigrants in the Netherlands. *Int J Publ Health* 2010;55(5):421–8.
30. Tudor Hart J. The Inverse Care Law. *Lancet* 1971;297(7696):405–12.

31. Woodward A, Howard N, Wolffers I. Health and access to care for undocumented migrants living in the European Union: a scoping review. *Health Policy & Planning* 2013.
32. Hudson AL, Nyamathi A, Greengold B, Slagle A, Koniak-Griffin D, Khalilifard F, et al. Health-seeking challenges among homeless youth. *Nursing Res* 2010;59(3):212.
33. Edland-Gryt M, Skatvedt AH. Thresholds in a low-threshold setting: an empirical study of barriers in a centre for people with drug problems and mental health disorders. *Int J Drug Policy* 2013;24(3):257–64.
34. Minh-Nguyet N, Venne T, Rodrigues I, Jacques J. Why and according to what consultation profiles do female sex workers consult health care professionals? A Study Conducted in Laval, Québec. *Health Care Women Int* 2008;29(2):165–82.
35. Williamson DL, Stewart MJ, Hayward K, Letourneau N, Makwarimba E, Masuda J, et al. Low-income Canadians' experiences with health-related services: implications for health care reform. *Health Policy* 2006;76(1):106–21.
36. Loignon C, Hudon C, Goulet É, Boyer S, DE Laat M, Fournier N, et al. Perceived barriers to healthcare for persons living in poverty in Quebec, Canada: the EQUIhealThY project. *Int J Equity Health* 2015;14(1):4.
37. Wen CK, Hudak PL, Hwang SW. Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *J Gen Intern Med* 2007;22(7):1011–17.

38. Nickasch B, Marnocha SK. Healthcare experiences of the homeless. *J Am Acad Nurse Pract* 2009;21(1):39–46.
39. Asgary R, Segar N. Barriers to health care access among refugee asylum seekers. *J Health Care Poor Underserved* 2011;22(2):506–22.
40. McGorrian C, Frazer K, Daly L, Moore RG, Turner J, Sweeney MR, et al. The health care experiences of Travellers compared to the general population: The All-Ireland Traveller Health Study. *J Health Serv Res Policy* 2012;17(3):173–80.
41. Neale J, Tompkins C, Sheard L. Barriers to accessing generic health and social care services: a qualitative study of injecting drug users. *Health & Social Care Commun* 2008;16(2):147–54.
42. Campbell R, Klei A, Hodges B, Fisman D, Litto S. A comparison of health access between permanent residents, undocumented immigrants and refugee claimants in Toronto, Canada. *J Immigrant & Minority Health* 2014;16(1):165–76.
43. Biswas D, Kristiansen M, Krasnik A, Norredam M. Access to healthcare and alternative health-seeking strategies among undocumented migrants in Denmark. *BMC Public Health* 2011;11:560.
44. Folch C, Lazar C, Ferrer L, Sanclemente C, Casabona J. Female sex workers and access to social and health services in Catalonia: Influence of region of origin and place of work. *AIDS Care* 2013;25(8):1033–38.

45. Newbold KB, Cho J, McKeary M. Access to health care: the experiences of refugee and refugee claimant women in Hamilton, Ontario. *J Immigrant & Refugee Stud* 2013;11(4):431–49.
46. MacFarlane A, Dzebisova Z, Karapish D, Kovacevic B, Ogbemor F, Okonkwo B. Arranging and negotiating the use of informal interpreters in general practice consultations: experiences of refugees and asylum seekers in the west of Ireland. *Soc Sci Med* 2009;69(2):210–14.
47. Gelberg L, Gallagher TC, Andersen RM, Koegel P. Competing priorities as a barrier to medical care among homeless adults in Los Angeles. *Am J Public Health* 1997;87(2):217–20.
48. Kushel MB, Gupta R, Gee L, Haas JS. Housing instability and food insecurity as barriers to health care among low-income Americans. *J Gen Inter Med* 2006;21(1):71–7.
49. Bade E, Evertsen J, Smiley S, Banerjee J. Navigating the health care system: a view from the urban medically underserved. *Wisconsin Med J* 2008;107(8):374–9.
50. Van Cleemput P, Parry G, Thomas K, Peters J, Cooper C. Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study. *J Epidemiol Commun Health* 2007;61(3):205–10.
51. Greenfields M, Brindley M. Impact of insecure accommodation and the living environment on Gypsies' and Travellers' health. *Traveller Movement & Bucks New University*. 2016.  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/fil](https://www.gov.uk/government/uploads/system/uploads/attachment_data/fil)

[e/490846/NIHB - Gypsy and Traveller health accs.pdf](#). Accessed 14 Jul 2016.

52. Mellor R, Lovell A. The lived experience of UK street-based sex workers and the health consequences: an exploratory study. *Health Promot Int* 2011;27(3):311–22.
53. Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;6(1):35.
54. Richard L, Furler J, Densley K, Haggerty J, Russell G, Levesque J-F, et al. Equity of access to primary healthcare for vulnerable populations: the IMPACT international online survey of innovations. *Int J Equity Health* 2016;15(1):64.
55. Health Service Executive Public Health Profile Working Group. Limerick City Health Profile. 2015.  
<http://www.lenus.ie/hse/bitstream/10147/584020/1/Limerick+City.pdf>. Accessed 22 May 2016.
56. Irish College of General Practitioners & Irish Cancer Society. Access to diagnostics used to detect cancer. 2016.  
[http://www.cancer.ie/sites/default/files/content-attachments/icgp\\_irish\\_cancer\\_society\\_report\\_-\\_access\\_to\\_diagnostics\\_to\\_detect\\_cancer.pdf](http://www.cancer.ie/sites/default/files/content-attachments/icgp_irish_cancer_society_report_-_access_to_diagnostics_to_detect_cancer.pdf). Accessed 28 June 2016.

57. O'Reilly-de Brun M, De Brún T. The use of Participatory Learning & Action (PLA) research in intercultural health: some examples and some questions. *Translocations: Migrat Soc Change* 2010;6(1).
58. de Brun T, O'Reilly-de Brun M, O'Donnell CA, MacFarlane A. Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology for primary healthcare implementation research. *BMC Health Serv Res* 2016;16(a):346.
59. Chambers R. The origins and practice of participatory rural appraisal. *World Dev* 1994;22(7):953–69.
60. de Brun T, Du Vivier E. *Own Goals and Penalties: A Study of the Needs of Socially-Excluded Males in Dublin Inner City*. Dublin: Dublin Inner City Partnership and Dublin City Council. 2008.  
<http://www.lenus.ie/hse/bitstream/10147/296789/1/owngoalsandpenalties.pdf>  
Accessed 28 June 2016.
61. DePoy E, Gitlin LN. *Introduction to research: Understanding and applying multiple strategies*. 5th ed. Maryland Heights, MO: Elsevier Health Sciences; 2015.
62. O'Reilly-de Brun M, De Brún T. *Participatory Learning and Action (PLA) training manual – Internal document*. Centre for Participatory Strategies. Galway, Ireland, 2011.
63. O'Reilly-de Brún M, MacFarlane A, de Brún T, Okonkwo E, Bokanga JSB, Silva MMD, et al. *Involving migrants in the development of guidelines for*

communication in cross-cultural general practice consultations: a participatory learning and action research project. *BMJ Open* 2015;5(9).

64. McMenemy R, Tierney E, MacFarlane A. Addressing the long-term impacts of aphasia: how far does the Conversation Partner Programme go? *Aphasiology* 2015;29(8):889–913.
65. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349–57.
66. Patton MQ. *Qualitative evaluation and research methods*. 2nd ed. London: Sage; 1990.
67. Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, et al. Reaching the hard-to-reach: A systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol* 2014;14(1):1–29.
68. Casey MA, Krueger R. *Focus groups: practical guide for applied research*. 3rd ed. Thousand Oaks, CA: Sage; 2000.
69. McMenemy R, Tierney E, MacFarlane A. Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study. *Aphasiology* 2015;29(8):914–38.
70. Silverman D. *Interpreting qualitative data: Methods for analysing talk, text and interaction*. 4th ed. London: Sage; 2011.

71. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101.
72. Mays N, Pope C. Rigour and qualitative research. *Br Med J* 1995;311(6997):109.
73. Devers K. How will we know ‘good’ qualitative research when we see it? Beginning the dialogue in health services research. *Health Serv Res* 1999;34(5 Pt 2):1153.
74. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. 4th ed. London: Sage; 2013.
75. Morse JM. Determining sample size. *Qual Health Res* 2000;10(1):3–5.
76. Schanzer B, Dominguez B, Shrout PE, Caton CLM. Homelessness, health status, and health care use. *Am J Publ Health* 2007;97(3):464–9.
77. Noël L, Fischer B, Tyndall MW, Bradet DR, Rehm J, Brissette S, et al. Health and social services accessed by a cohort of Canadian illicit opioid users outside of treatment. *Can J Publ Health-Rev Can Sante Publique* 2006;97(3):166–70.
78. Dahlgren G, Whitehead M. European strategies for tackling social inequities in health – Levelling up Part 2. WHO Regional Office for Europe. 2006. [http://www.euro.who.int/\\_data/assets/pdf\\_file/0018/103824/E89384.pdf](http://www.euro.who.int/_data/assets/pdf_file/0018/103824/E89384.pdf). Accessed 10 Nov 2015.
79. Sinnott S-J, Buckley C, O’Riordan D, Bradley C, Whelton H. The effect of copayments for prescriptions on adherence to prescription medicines in

- publicly insured populations; a systematic review and meta-analysis. PLoS ONE 2013;8(5):e64914.
80. World Health Organization. Universal health coverage (UHC) fact sheet N°395. 2015. <http://www.who.int/mediacentre/factsheets/fs395/en/>. Accessed 12 Mar 2016.
81. Commission on Social Determinants of Health. Closing the gap in a generation: Health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health. World Health Organization. 2008. [http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/43943/1/9789241563703_eng.pdf). Accessed 8 May 2015.
82. Hadgkiss EJ, Renzaho AMN. The physical health status, service utilisation and barriers to accessing care for asylum seekers residing in the community: a systematic review of the literature. *Austral Health Rev* 2014;38(2):142–59.
83. Christiani A, Hudson AL, Nyamathi A, Mutere M, Sweat J. Attitudes of homeless and drug-using youth regarding barriers and facilitators in delivery of quality and culturally sensitive health care. *J Child Adolesc Psychiatr Nurs* 2008;21(3):154–63.
84. Martins DC. Experiences of homeless people in the health care delivery system: a descriptive phenomenological study. *Public Health Nurs* 2008;25(5):420–30.
85. Allport GW. The effect of contact. In: *The nature of prejudice*. 1st ed. Reading, MA: Addison-Wesley; 1954.

86. O'Carroll A, O'Reilly F. There's a hole in the bucket: an analysis of the impact of the medical card review process on patient entitlement to free health care. *Irish Med J* 2008;101(1):10–12.
87. Government of Ireland. Equal Status Act. 2000.  
<http://www.irishstatutebook.ie/eli/2000/act/8/enacted/en/pdf>. Accessed 14 May 2016.

## **Chapter 7: Integration of Findings**

### **7.1 Introduction:**

The aim of this study was to conduct a multi-perspectival theoretically informed, empirical analysis of the implementation of community participation on Primary Care Teams (PCTs) in Ireland. The objectives were to compare perspectives across stakeholders involved in implementing community participation on PCTs and identify levers and barriers to implementation of community participation on PCTs.

To address the aim and objectives, integration of qualitative and quantitative data at the interpretation and reporting level informed by NPT was the integrated data analysis approach in this PhD as outlined in Chapter 3. Data were analysed separately for the three studies (outlined in Chapters, 4, 5 and 6) and findings from these three papers were then further extracted and deductively coded onto the four NPT constructs for data integration and analysis.

The following questions were used to synthesis the findings across the three papers.

How do stakeholders involved in PCTs and wider primary care context make sense of community participation on PCTs?

How and why do stakeholders get involved in community participation on PCTs?

What do stakeholders need to enact community participation on PCTs in daily practice?

How do stakeholders evaluate the impact of community participation on PCTs?

(See Appendix 6 Triangulation Protocol for Integrated Analysis).

Levers and barriers to embedding community participation on PCTs were also explored via NPT lens (see Table 7.1).

This chapter maps and integrates findings about community participation on PCTs across the three papers outlined in Chapters 4, 5 and 6.

### **Participants in this analysis:**

There were 629 participants representing five stakeholder groups in this analysis. Data was gathered using a mixture of methods including a national survey, interviews and focus groups employing participatory learning and action techniques, which informed the multi-perspectival analysis of community participation on PCTs in action (see Chapter 3, Table 3.1). Participants represented community representatives, HSE service planners and policy makers, HSE health professionals and practitioners working on PCTs, GPs and patients or members of marginalised groups.

## **7.2 Data integration: Mapping findings across the three papers onto NPT constructs**

The findings across the three papers were mapped onto NPT constructs and questions were posed of the data about the strength of the construct across the three papers. Findings per construct and per paper were analysed asking “how strong is the implementation of community participation on PCTs?” This was similar to the working definition for strong implementation as outlined in Paper 2 Chapter 5 (see Box 5.1). For this study, this method was also used as a benchmark to classify the implementation as strong, moderate or weak. The data was further analysed to explore levers and barriers to implementation of practice ‘on the ground’.

The findings are set out under NPT constructs below.

### **7.2.1 Coherence: How do stakeholders involved in PCTs and wider primary health care context make sense of community participation on PCTs?**

There were shared views about the potential value of community participation on PCTs across stakeholders. In paper 2, all participants in the study considered that community participation on PCTs was about meaningful reciprocal relationships between stakeholders to represent the voice of the community in primary health care delivery generally and more specifically at the PCT meetings. Managers and policy makers saw this as a very valuable mechanism for consultation with communities.

There was a general consensus among community representatives in paper 2 that the role of community representatives was to feed ideas to the PCT about service needs of the community. In this paper community representatives saw the value of their role as a means to empower community members, find their voice and encourage participation. They saw their role as a catalyst for change in the dynamic of PCTs.

However, in paper 1, this relevance of community participation on PCTs is questioned as this was not considered an important requirement for PCT working.

One can infer from this that if community participation was not deemed important or necessary to promote team working then implementing it effectively as part of team processes will be difficult from the outset.

This divergence of views may be explained by the lack of shared understanding about the role of community participation between those who are more involved with

its implementation or have experience of it in practice, versus those in the wider network in the healthcare system who do not have this experience. In paper 2, community representatives, HSE managers and health care professionals directly involved in community participation in PCTs agreed that there is a lack of shared understanding among the wider network of PCT members about community participation on PCTs and what the role of community representatives entailed. This was borne out in the finding that for GPs, community representatives on PCTs prompted a fear that they would lose control of their work, and this was a concern for them. There were also different understandings of what is meant by community participation on PCTs across various PCT stakeholders and this means it is difficult to implement as part of team processes. This dissonance in coherence about community participation creates problems for implementation of community participation on PCTs as is borne out in findings about enactment of community participation on PCTs discussed later.

The overall finding from this analysis is that coherence was moderate. Following NPT, a shared view about the potential value of community participation on PCTs across stakeholders would be a lever to implementation and that is not the case for community participation on PCTs. Stakeholders hold different understandings of community participation on PCTs, and this acts as a barrier to embedding this work as part of team processes.

### **7.2.2 Cognitive Participation: How and why do stakeholders get involved in community participation on PCTs?**

Many stakeholders (community representatives, health care professionals) get involved in this way of working because of champions who drive the work of implementing community participation on PCTs. In Paper 2, buy-in to this way of working for community representatives happened because they were invited to be a representative on the PCT by champions of the JI who were known to them. This ‘champion’ was usually a community development worker, project coordinator or PCT work colleague and were described as being passionate and committed. For many participants, (in particular, community representatives and health care professionals) personal motivations were at play. In paper 2, community representatives became involved because they lived locally and had a vested interest in the area. It was also an opportunity for them to share information with the PCT about particular community projects with which they were involved. For some health professionals, e.g., social workers, community development workers, it fitted with the ethos of their professional role for example, promoting social determinants of health, involvement with community health and well-being programmes.

Motivations for policy makers were different; community participation on PCTs connects with the Primary Care Strategy and was an opportunity for them to “activate” policy in practice. In paper 3, champions were Traveller Health Advocates who undertook training to improve their literacy and advocacy skills and their knowledge of a range of health topics so that they could work to improve the health of their community. This would then enable them to support access to primary health care for other members of their community. These roles could be seen as ‘boundary spanners’.

Positive relationships supported buy in to the work as demonstrated in papers 2 and 3. In paper 2, these relationships were with the champions mentioned above and in paper 3, advocates/key workers provided a key role in supporting this work in practice. The key workers supported participants from homeless, drug using and sex working communities to understand and navigate the complex primary health care system and offered practical supports to do this.

The overall finding from this analysis is that cognitive participation was strong. Following NPT, these data show that champions support this work on the ground and this supports implementation of the work. Personal motivations act to enhance the work. Professional ethos of team members and existing positive relationships support implementation.

### **7.2.3 Collective Action: What do stakeholders need to enact community participation on PCTs in daily practice?**

There were health systems structures which impeded the enactment of community participation work. Overall, PCTs are not functioning uniformly across the country and this creates problems for implementation of community participation on PCTs. In paper 1, the majority of respondents reported little or no progress at all with implementation of the Primary Care Strategy in Ireland in general. Only 1% of respondents reported complete implementation of formal PCTs. GPs and Nurses were most negative about PCT implementation and it is likely that this impacted

their perceptions of community participation on these teams. Supporting this finding in paper 2, all participants irrespective of role and across sites felt that the PCTs were not at a stage of development for community participation to operate effectively. All participants agreed that this was a major barrier to the enactment of community participation on PCTs. In Paper 1, this was borne out in the finding that only 10% of respondents reported that there was community representation on their PCT.

Resources for staff and communities are important to enact community participation on PCTs. In Paper 2, all participants (HSE management, health care professionals and community representatives) talked about the importance of a paid role to coordinate this work. Despite this, in paper 1, community participation was ranked as one of the least important factors to promote effective team working. These findings were consistent across the three largest groups of health care professionals in the study (GPs, nurses, clinical therapists). If community participation is not considered an important factor to promote team working, then it will be hard to convince teams to implement it in practice especially without the requisite resources.

There were differences in opinion across stakeholders about the operationalisation of this work. In paper 2, participants in local HSE management roles talked about extensive planning and consultation that had to take place to maintain everyone's involvement to operationalise community participation on PCTs. GPs spoke about their frustration with PCT working itself, the different styles of working involved in implementing community participation on PCTs and the challenge of this for them. They were also frustrated about the community development style of working, which

they felt took up a lot of time and didn't necessarily require their input. It appears that GPs view this work as something separate from their PCT activity and is not viewed by them as work that they could or should integrate into their work in primary health care. It may also account for the finding in paper 1 that community participation on PCTs was not considered an important factor for effective team working.

Participants in two papers described their experiences of enacting community participation on PCTs. Across the perspectives reported, despite good relationships which supported *buy-in* as described in cognitive participation above, relationships in *enacting* community participation on PCTs were strained. Community representatives felt their role was tokenistic at PCT meetings and HSE management felt that GPs did not appreciate the role of community representatives on the PCT. In paper 2 community representatives who participated in PCT meetings, felt there was a lack of clarity among some health care professionals about the precise role and purpose of the community representatives at those meetings. There was also concern expressed by some health care professionals about representativeness of community members. This created mistrust between team members. This finding resonates with the lack of coherence about community representatives' roles across stakeholders discussed in Coherence above. If there is not a shared understanding of the purpose of community participation across team members then clarity about roles in team meetings will be missing, creating mistrust between team members.

Where positive relationships did exist, they were key to successful enactment of community participation on PCTs. For example, in papers 2 and 3 advocates/key workers provided a key role in supporting this work in practice and supporting access to primary health care community projects. These good relationships between community representatives and health care professionals resulted in the successful roll out of community participation activities or projects such as mental health awareness days, health promotion activities and parenting programmes.

However, returning to the relevance of health system structures discussed earlier, findings in paper 3 about the ‘two-tier’ healthcare system – and the nature of the ‘opt-in’ system for publicly funded healthcare meant that many marginalised groups are disadvantaged. The obstacles described in paper 3 such as the attitudes of health care professionals, the structural problems with access, and literacy difficulties for some marginalised communities were perceived to act as a disincentive to engage with PCTs (where they do exist) and were a barrier to healthcare utilisation by these groups. Participants across all six participant groups in paper 3 explained that often the structure of primary health care services made it difficult to engage with and access them. Furthermore, lack of understanding by health professionals of the lived experience of marginalised communities was identified as a barrier in paper 3. Many participants across all groups felt healthcare providers did not understand the complexity of problems faced on a daily basis by patients from the marginalised groups. Without a true understanding of the ‘lived experience’ of these patients, it can be difficult for professionals to improve their access to primary care, and ultimately their health. This social distance between the providers and marginalised patients can make community participation in PCTs even more difficult to enact. If

health professionals do not understand these obstacles and cannot assist with the access to primary health care services, then how can they be expected to work with these communities as equal partners at PCT meetings/community health fora or in delivery of a community health initiative?

The overall finding from this analysis is that Collective Action was moderate. Following NPT, the data show that PCTs are not functioning uniformly across the country and this creates a system level problem for implementation of community participation on PCTs. A paid role to coordinate the work is essential but the lack of resources for PCT implementation and for community participation on PCTs impedes implementation. Collaborating with key workers and good relationships act as facilitators to engage with the primary healthcare system generally and PCTs more specifically. However, the structural elements of primary care services and social distance between providers and marginalised communities impedes implementation and thereby limits their involvement as members of the PCTs. Lack of clarity about the role of the community representatives and mistrust between team members impedes the work of the team. This maps onto lack of coherence across stakeholders as discussed above.

#### **7.2.4 Reflexive Monitoring: How do stakeholders evaluate the impact of community participation on PCTs?**

Formal evaluation of community participation on PCTs was limited. In paper 2, all participants (community representatives, health care professionals, and HSE management) agreed that community participation on PCTs is hard to evaluate or

measure. Community participation on PCTs was measured formally by a Key Performance Indicator (KPI) (a count of the number of community representatives on the PCT) by the HSE nationally. However, this metric, on its own, was considered to be very limited and does not capture the breadth and variety of activities that comprise community participation activities. This was cited as problematic particularly by HSE management.

Informal evaluations were more common. The biggest perceived benefit of community participation on PCTs from informal evaluations cited across all stakeholders and case study sites in paper 2 was increased awareness about services available in the community and among HSE personnel (health care professionals and management) about community projects and the role of community workers in these projects. In papers 2 and 3 community representatives felt that community participation on PCTs improved awareness and thus service delivery for the local population, resulted in more efficient use of resources and connected GPs with their community.

In paper 2, many community representatives reported that this work also led to personal benefits such as empowerment. The training and skill development they received supported their career paths. They also cited mutual learning for community representatives and clinicians. They educated clinicians at PCT meetings about the value of community participation and this resulted in improved networking across community regions to share resources. However, for some stakeholders (community representatives and GPs) there was disappointment that nothing happened as a result

of the work (no real recognition of the role of community representatives, no significant development of primary health care services), and there was a sense of lost opportunity and that nothing had really changed (PCTs were still struggling to be implemented and team meetings were operating in the same way without significant input from community representatives).

Across all participant groups (community representatives, health care professionals, HSE management and GPs) in paper 2 there was uncertainty about the future of community participation on PCTs. It is a challenge to sustain community participation on PCTs. In particular, the lack of resources to sustain the PCTs was cited as a challenge for the future. HSE Management in particular felt that this work needs to be built into professional roles and there needs to be more education about the practicalities of enacting this work.

The overall finding from this analysis is that Reflexive Monitoring was weak. Following NPT, the data shows that informal evaluations are valuable but formal appraisals of community participation on PCTs are rare and limited and this is problematic for embedding the work. The potential for the personal and collective benefits of community participation on PCTs were recognised but limited in its potential to transform services in its current format.

### 7.3 Key messages from the PhD study

Findings from the NPT analysis presented above were further categorised as levers and barriers to implementation (see Table 7.1).

NPT was also used to examine the interactions between coherence, motivations, enactment and appraisal of community participation on PCTs. (see Fig 7.1)

*Levers* to community participation are champions who support the work and personal motivations of community representatives and health care professionals who support buy in to get the work off the ground.

Positive relationships where they exist enhance practice on the ground and *support* roll out and enactment of community participation activities.

Following findings about coherence, lack of clarity among some health professionals about the precise role of the community representatives and lack of respect by PCT members for the role of the community representative *impede* enactment of the work.

The structural barriers and the ‘two-tier’ primary health care services *impede* the implementation of PCTs and this acts as a *barrier* to implementing community participation on these PCT as does lack of resources to enact the work.

Complex personal and structural barriers to accessing primary healthcare for marginalised groups' make it difficult to engage with marginalised communities thereby *hindering* community participation of these groups on PCTs.

Positive informal evaluations of the work are reported but formal appraisals of the work are rare and do not capture the complexity of the work thereby *impeding* the sustainability and transferability of the work.

The conclusion is that the barriers outweigh the levers in this analysis. The weighty impediments reported under collective action overshadow the positive levers to implementation reported under cognitive participation and aspects of collective action. Where stakeholders hold different coherence of community participation on PCTs, this acts as a barrier to enacting community participation on PCTs in practice, and evaluating its effectiveness.

Overall, the lack of universal coherence about the work and the poor implementation of PCTs impacts buy in, enactment and appraisals of the work thereby making implementation challenging and sustainability unlikely.

**Table 7.1: Levers and barriers to community participation on primary care teams (PCTs) using NPT constructs to evaluate implementation; synthesis of findings across the research papers in this PhD**

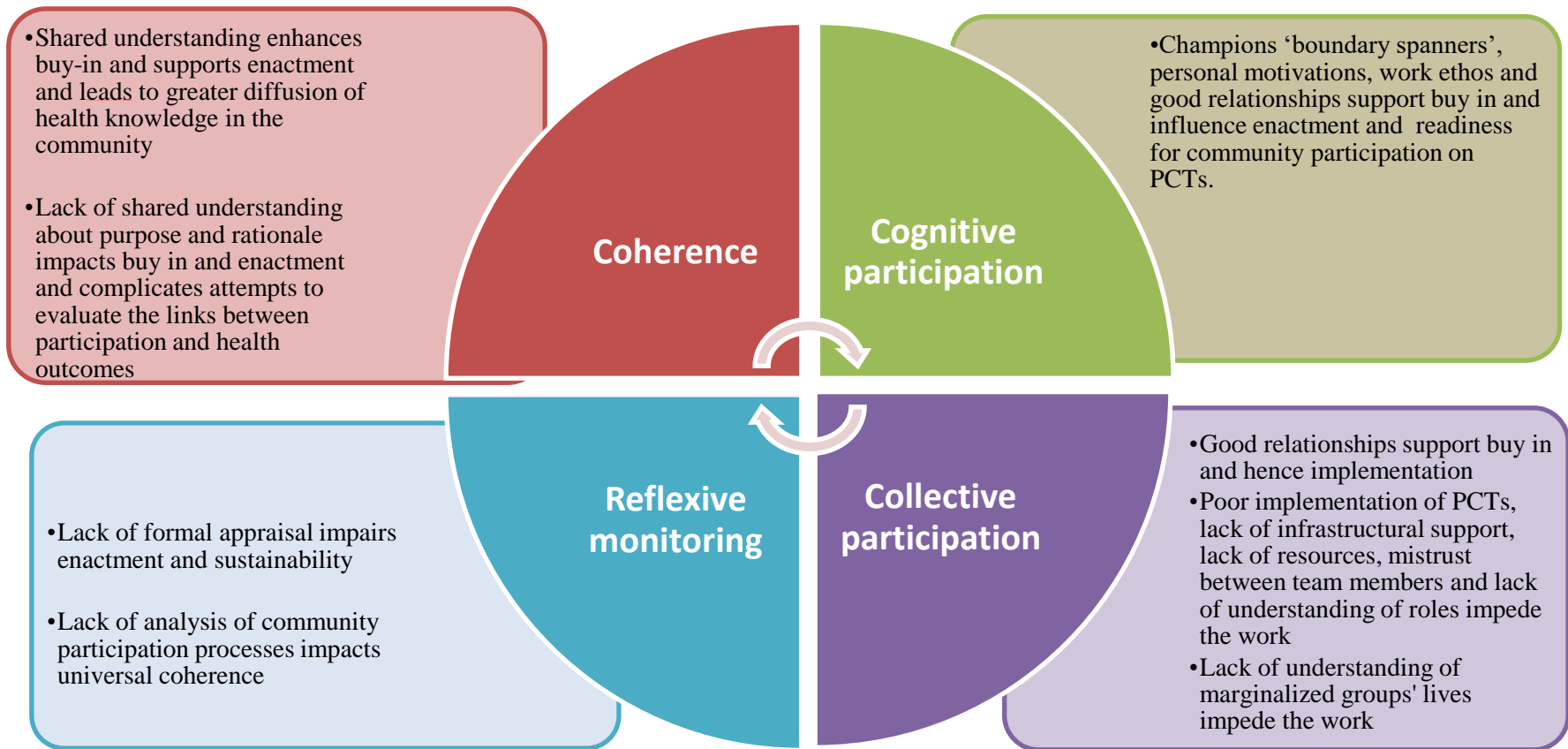
| <i>NPT Construct</i>  | <i>Lever</i>  | <i>Barrier</i>  | <i>Status</i> |
|---|---|---|---------------|
| <p><b>Construct 1:<br/>Coherence</b></p> <p>How do stakeholders involved in PCTs and wider primary health care context make sense of community participation on PCTs?</p> | <p>Shared views about potential value of community participation on PCTs across stakeholders who have been closely involved in pilot projects <b>P2</b>.</p>  | <p>Lack of shared understanding of wider stakeholder community about the role of community representatives on PCTs <b>P2</b>.</p> <p>Community participation is not considered an important resource for PCT working except by managers and policy personnel who are charged with implementation of Primary Care and related strategies <b>P1</b>.</p> <p>Community representatives and other PCT members (e.g.GP and Nurses) hold different understandings of community participation on PCTs <b>P2</b>.</p> | Moderate      |
| <p><b>Construct 2:<br/>Cognitive Participation</b></p> <p>How and why do stakeholders get involved in community participation on PCTs?</p>                                | <p>Champions employed by HSE <b>P2</b>.</p> <p>Personal motivations enhance the work <b>P2</b>.</p> <p>Fits with social determinants of health or professional ethos of certain primary care team members (e.g., social workers, community development workers) <b>P2</b>.</p> <p>Existing positive relationships community representatives and</p> |   | Strong        |

|   |   |  |          |
|---|---|--|----------|
|   | health care professionals on the ground support buy- in <b>P2, P3.</b>  |  |          |
| <p><b>Construct 3:</b><br/><b>Collective Action:</b></p> <p>What do stakeholders need to enact community participation on PCTs in daily practice?</p> | <p>Paid role to coordinate the work <b>P2.</b></p> <p>Examples of practical supports identified e.g., navigation of health system <b>P3.</b></p> <p>Collaborations with key workers <b>P3.</b></p> <p>Positive relationships support the work and act as facilitators to engage with the primary healthcare system <b>P3.</b></p> | <p>Lack of clarity among some health professionals about the precise role of the community representatives at PCT meetings <b>P2.</b></p> <p>Lack of respect by PCT members for role of community representative <b>P2.</b></p> <p>Concern about representativeness of community members <b>P2.</b></p> <p>Community representatives and patients can identify priorities for primary health care provision but enactment of these priorities takes commitment and buy- in from management <b>P2 P3.</b></p> <p>Lack of resources for PCTs and for community participation on PCTs <b>P1 P2.</b></p> <p>Extensive planning and consultation required to maintain involvement and to organise community participation activities <b>P2 P3.</b></p> <p>Styles of team working differ across professionals e.g. community development workers vs GPs <b>P2.</b></p> <p>PCTs are not functioning uniformly across the country <b>P1 P2.</b></p> <p>‘Two-Tier’ healthcare system and the structure of primary health care services make it difficult to engage with marginalised communities <b>P3.</b></p> | Moderate |

|   |  |  |      |
|---|--|--|------|
|   |  | Complicated personal and structural barriers to accessing primary healthcare for marginalised groups' mean it is difficult for them to access health care and so makes it difficult for them to be involved as members of PCTs <b>P3</b> .                 |      |
| <p><b>Construct 4:</b><br/><b>Reflexive Monitoring</b></p> <p>How do stakeholders evaluate the impact of community participation on PCTs?</p> | <p>Positive outcomes are reported from informal evaluations <b>P2</b>.</p> <p>Improved service delivery for the local population, results in more efficient use of resources and connects GPs with their community <b>P2 P3</b>.</p> <p>Leads to increased awareness about primary health care services <b>P2</b>.</p> | <p>Formal evaluations are rare <b>P2</b>.</p> <p>Formal HSE KPI is limited and on its own does not cover the complexity and value of the work <b>P2</b>.</p> <p>Uncertainty about the sustainability of the community participation on PCTs <b>P2</b>.</p> | Weak |

#### **7.4 Conclusion**

It is a challenge to sustain community participation on PCTs in an environment where PCTs are struggling to be established. The data about levers and barriers reported are important because it provides clear information about activities, processes and relationships that can fuel the implementation of community participation on PCTs. This knowledge can help create change through development of wider networks and supportive relationships which are crucial to embed community participation on the ground which may be transferred to other primary health care settings.



**Figure 7.1: Figure showing intersection of NPT constructs**

## **Chapter 8: Discussion**

### **8.1 Introduction**

The findings from each study have been discussed individually in the published papers (Chapters 4-6). The principal findings from all three studies, as they relate to each other, are drawn together in Chapter 7. Here, a summary of findings from the three papers is presented and the key messages arising from the PhD findings are discussed with reference to the literature, primary health care policy, and policy implementation theory. A methodological critique of this PhD is presented, including a discussion about thesis by publication, a critical reflection on learning and study limitations. All of this is drawn together to develop conclusions about the practice of community participation on PCTs in Ireland. These conclusions are then developed to make recommendations for policy and practice.

### **8.2 Summary of Findings**

In Paper 1 (Chapter 3), respondents across all disciplines viewed interdisciplinary team working as important. They also agreed on lack of progress of implementation of formal PCTs. Nurses and GPs were more negative than clinical therapists about the progress of implementation. GPs were more negative about the effectiveness of the Primary Care Strategy to promote interdisciplinary working. There was some disagreement about which resources are most important for effective PCT working. Protected time for meetings and capacity to manage workload for meetings were rated as very important factors for effective team working by GPs, clinical

therapists and nurses. A building for co-location of teams was rated as an important factor by nurses and clinical therapists though was rated less important by GPs.

Payment to attend meetings and contractual arrangements were considered important resources by GPs but not by nurses or clinical therapists. There was agreement across GPs, clinical therapists and nurses that community participation and waiting list systems were the least important factors for effective PCT working.

Overall findings show that effectiveness was not highly rated overall with some groups (GPs) more negative than other groups.

In Paper 2 (Chapter 5), the various stakeholders had a shared understanding of the value of community participation on PCTs. Motivations to get involved in this work varied, but were strong overall. Challenges to enacting community participation on PCTs included problems with the functioning of PCTs and a lack of clarity and confidence in the role of community representatives at PCT meetings. Informal appraisals were positive but formal appraisal was limited. The implementation and sustainability of community participation on PCTs in Ireland will be limited unless the functioning of PCTs is stronger and there is increased confidence and clarity on community representatives' roles at PCT meetings. More refined methods for formal appraisals of the work are needed.

In Paper 3 (Chapter 6), barriers and facilitators to primary health care access from the perspective of migrants, Irish Travellers, homeless people, drug users, sex workers and people living in deprivation, were explored and priorities for action with regard to primary care provision identified. Four overarching themes were identified: the home environment, the effects of the 'two-tier' healthcare system on

engagement, healthcare encounters, and the complex health needs of many in those groups. The study demonstrated that there are many complex personal and structural barriers to accessing primary healthcare for marginalised groups. There were shared and differential experiences across the groups. If steps are taken to address these, there is scope to impact on more than one marginalised group and to address the existing health inequities.

Synthesis of findings across the three papers:

In this study coherence about community participation on PCTs was moderate. There were mixed views about the potential value of community participation on PCTs across stakeholders. This may be because stakeholders hold different understandings about what this work entails, and this impedes the work. Cognitive participation was strong. Champions drive the work of implementing community participation on PCTs, but motivations vary across stakeholders. Existing positive relationships support buy-in. Collective action was also moderate. PCTs are not functioning uniformly across the country and this creates problems for implementation of community participation on PCTs. Impediments to enacting the work include lack of resources, and lack of clarity among some health professionals about the precise role of the community representatives on PCTs, perceived tokenism and lack of understanding of the lived experience of marginalised communities. The structures of primary health care services can make it difficult for marginalised groups to engage. Relationships can support or impede community participation on PCTs. Reflexive monitoring was weak. Formal evaluations were inadequate, although informal appraisals of community participation on PCTs were positive. The biggest benefit cited was increased awareness about services available in the community and

among HSE personnel about community projects. There was uncertainty about the future of community participation on PCTs however, and agreement that it is a challenge to sustain this way of working.

### **8.3 Comparison with Literature**

In this study coherence was moderate. Participants reported that there was some confusion about what the work involved and what community participation meant to different stakeholders. This links with the definitional challenges and confusion in the literature around conceptualisation e.g., [1-5]. Despite the policy vision for community participation via PCTs, clarity and agreement between different stakeholder groups about the roles of community representatives was problematic, as cited elsewhere, [6-8] and GP concerns about the potential for negative impact on their practices was reported [9]. Before embarking on community participation, it is important that all stakeholders have a shared understanding of the purpose and rationale [3]. Goals and expectations with respect to participation must be mutually identified and accepted [10]. From an NPT perspective, this lack of clarity and coherence about the work will undermine the enactment and appraisal of community participation in PCTs in practice. There is a need for a coherence across all stakeholders to enhance understanding, and thereby influence engagement and readiness for, as well as appraisal of community participation on PCTs.

Cognitive participation was strong in this study. As reported elsewhere visionary leaders who are committed to working with communities were an essential ingredient of encouraging buy-in and commitment to community participation e.g.,

[11]. This echoes Abelson et al, who concluded that there needs to be buy in at community level, especially by civic leaders, to mobilise citizen deliberation [12]. Similar to elsewhere, people who have had experience of this way of working are more willing to spend time on participation in primary health care [13]. Specifically in this study, community workers acted as what have been identified elsewhere in the literature as “boundary spanners” [11, 14-16] which meant that they became advocates, and translated and mediated between local people and professionals [9, 11, 15-17]. Boundary Spanners are known to be an effective lever to implementing community participation initiatives in practice [18].

Rewards for community participants are largely philosophical, emotional and symbolic compared to health professionals and managers for whom participation often has tangible professional and career advantages [10]. This finding was borne out in this study. Health professional participants were motivated by their professional ethos and role, but community participants were motivated by their residence in a particular area or their involvement with a personal project which has more emotional and philosophical foundations.

Collective action was moderate. Predisposing conditions for community participation in health include a political climate which accepts and supports active community participation and policy legislation and resource allocation which take account of regional and local needs [10]. These conditions were in place for community participation on PCTs to be enacted via the implementation of the 2001 Irish primary care policy (Paper 1 Chapter 4) and a roll out of an initiative to support disadvantaged communities to participate in primary health care via the Joint

Initiative (Paper 2 Chapter 5) and local action research projects (Paper 3 Chapter 6). However, the structures with which to enact this way of working were not functioning. Participants across the three papers reported that there was a problem with implementation of PCTs, echoing findings from elsewhere where PCT working has been described as ‘very challenging’ [19-22] and this inevitably impaired capacity to do the work. Furthermore, lack of infrastructure, and lack of skills or confidence pose a barrier to community participation [12, 23, 24]. In this study, across the three papers, there was evidence that there was lack of infrastructural support for PCTs. Trusting relationships between participants support community participation [15, 25, 26] but in this study there was mistrust between team members about role and representativeness of community members. This lack of clarity and agreement between stakeholder groups about the roles of community representatives remains a major obstacle to effective community participation [6-8, 27]. Determining who is a legitimate representative of the community is complex [10, 12, 28] and debatable [3] but is crucial to the perceived legitimacy of the representatives in the eyes of the population served. There was a lack of resources to embed the work, echoing the literature which reported that effort and time is needed to embed community participation [6-8, 10, 27] and to train and support workers [5, 29]. Therefore, it is a challenge to sustain community participation on PCTs in an environment where PCTs are struggling to be established.

The perceived poor attitudes of primary health care professionals towards patients from marginalised groups in this study resonates with findings from many other studies on this topic [30-34]. Living in a declining area has been shown to have a negative association with the willingness to spend time on community participation

[13] thus making community participation with marginalised groups more challenging. The findings from this PhD demonstrate the many complex challenges and layers of marginalisation cited elsewhere across primary health care settings [26] and highlights the need for a multifaceted approach when trying to engage marginalised communities in planning health care via statutory services like PCTs. Opening spaces for dialogue is not sufficient to ensure effective participation [26, 28]. Power imbalances [14, 48, 51, 86, 97, 98] can exclude lay people from decision-making processes as reported by marginalised groups in this study in paper 3, Chapter 6. Understanding, negotiating and contesting power, particularly with marginalised groups, remains an area which requires further research [24, 35-37].

Appraisal of community participation on PCTs was weak in this study. Informal evaluations were more common. The biggest perceived benefit of community participation on PCTs from informal evaluations cited was increased awareness about services available in the community and improved service access, utilisation, quality and responsiveness as reported elsewhere [4, 9, 25, 38-43]. Furthermore, community representatives perceived personal benefits of this work were related to self-confidence and personal empowerment as reported in the literature [3, 10, 23, 25, 38, 44, 45], as well as development of new skills and confidence to engage in new activities as reported by [24, 45]. Informal appraisal from participants reported that community participation resulted in health activities being more appropriate when the community was given greater control [3, 10, 24, 46] and this has the potential for greater diffusion of health knowledge in the community and greater use of local expertise [10].

There is also evidence from the literature that there are unintended negative consequences of community participation for some individuals, including exhaustion and stress, consultation fatigue and disappointment [44]. Although not measured as an outcome in this study there was a sense of frustration in paper 2, Chapter 5, that nothing had been achieved as a result of community participation efforts, however, this was not a common finding reported across participants.

A number of reviews examining the impact of community participation programmes on health outcomes concluded that there is a small but consistent body of evidence that community participation is associated with improved health outcomes [4, 38, 39]. In this thesis, health outcomes of community participation were not measured nor did they examine change from a baseline as is common [45], but there was a reported increase in awareness about health services available and this may in time improve health outcomes. Longitudinal research could explore this.

NPT was a useful heuristic to examine the levers and barriers to implementation of community participation on PCTs via the lens of NPT constructs. It was possible to disentangle experiences of implementing community participation as a process in real world settings from a variety of perspectives in order to examine other external influences. NPT examined the interactions between coherence, motivations, enactment and appraisal. In doing so, this study raises a number of questions, some of which were answered by this PhD and some of which remain unresolved. For

example, building and expanding on questions raised in paper 1, Chapter 4; Does the 'work' involved in enacting and embedding community participation on PCTs (collective action) make more sense (coherence) to different types of professionals because of their history of working in this way and their existing relationships and consequently, directives for interdisciplinary working (cognitive participation) via PCTs make more sense to them? In this thesis we conclude that this is the case. Community participation resonates with those most familiar with this way of working and is supported by existing relationships which is a lever to involvement in community participation initiatives. Does PCT working make more sense to certain stakeholders e.g., HSE employees compared with GPs because of how they understand their 'job'? (coherence). This was the case in this study. Does frequent involvement in PCT meetings or previous relationships between stakeholders (collective action) mean that interdisciplinary working makes more sense (coherence) and thus, enhances efforts to enact community participation and overcome any barriers to this way of working (collective action)? NPT suggests that attendance at PCT meetings would be more likely to enhance coherence of the work thus enhancing willingness to enact the work. This question remains to be empirically answered. Does a lack of understanding of the lived experience of marginalised groups by some professionals (coherence) impinge on community readiness to get involved (cognitive participation)? This study suggests it does but whether or not it impinges on their ability to be meaningfully engaged at meetings (collective action) remains unclear. Does the lack of coherence about the work (coherence) impede ability to form conclusions about outcomes (reflexive monitoring)? Or does the lack of formal appraisal of the work (reflexive monitoring) lead to reduced motivation to get involved (cognitive participation) and lack of trust

in the processes (collective action). Findings from this study suggest that this may be the case but further research is needed to clarify the exact relationship. Formal appraisals of community participation were largely absent and this relationship between coherence, cognitive participation and appraisal needs further explication.

As proposed in Chapter 7, NPT constructs can be seen as a jigsaw where each construct impacts the other. This theory shows that community participation needs to be embedded across entire health systems— from the microsystem level (individual practices) to the mesosystem (health care organisations) and the entire macrosystem (overall health system and government policy)[47]. NPT thus, allows the macro, meso and micro aspects of community participation to be drawn out and examined as a process rather than a one off intervention [48]. To complete the picture of what happens to enact community participation successfully on the ground on PCTs, one must consider stakeholders' understandings of the value of community participation on PCTs, the motivations of the various stakeholders involved, their interactions and relationships with one another as well as the political and policy climate and available resources and structures to support participation. Finally, to understand community participation on PCTs, one must have an understanding about the outcomes of the work. How these are measured and understood in turn impacts on coherence, motivations and enactment.

#### **8.4 Methodological Critique**

A methodological critique of the study design and the mixed methods case study approach has been addressed in Chapter 3. This section explores the strengths and limitations of the overall PhD study and discusses the value of using a publication route to explore the research aims and objectives in this study. Further discussion about quality and rigour in the research is outlined in Appendix 7.

The greatest strength of this thesis is that it is a theoretically informed mixed methods study incorporating three related but separate projects to explore a complex and little understood facet of primary health care. The three projects comprising the data across the three papers in this PhD offer a unique lens on the phenomenon of implementing community participation on primary care teams. One challenge in policy research is overcoming the many hurdles to accessing the many different actors, individuals, groups and networks involved in the policy process [147]. The multi perspectival analysis from across a variety of stakeholders offers an opportunity to explore implementation of primary health care policy in this context. The range of geographical locations, stage of development of PCTs and range of community, patient, health professional and policy stakeholder perspectives offers a holistic view of the topic which would have been difficult to achieve in one study alone. A particular strength is that it adds the unique voice of community representatives that is absent from the literature [39] using participatory methods that were valuable to elicit shared and differential views about community participation experiences. These methods were effective for engaging with marginalised groups in a significant way that saw them describing their experiences and defining their own needs and priorities.

The processes of community participation are highly complex and multi-faceted, and continual references to the term without acknowledging these complexities reflect a lack of analytical rigour [49]. The analytical rigor in this study was enhanced by drawing on a theoretical framework for implementation, highlighting the levers and barriers to implementation of community participation on PCTs across the multiplicity of stakeholder perspectives not reported elsewhere. Using theory-led research designs to explain the implementation and integration of multifaceted interventions may inform the development of strategies to embed their use in practice [50]. Thus, this study offers the opportunity for comparable analyses of similar initiatives in other health care jurisdictions [48, 51-53]. The use of theory to underpin data collection (as well as the design) and its application to data analysis across quantitative and qualitative methods in two studies provided a robust approach to the investigation of policy implementation and enhanced knowledge.

#### **8.4.1 Limitations**

Many of the thesis limitations have been already discussed in Chapters 4 to 6. This section discusses some additional important limitations that relate to integrating findings from the different strands of this thesis.

The size of the sample is important. Whilst the overall sample size (N=629) is a strength of this study, the sample size for individual studies of marginalized groups and community representatives (n=48) is small and as with all qualitative studies,

raises questions about the credibility and transferability of findings. However, the sample sizes represent a variety of settings reporting the range of experience across a variety of primary health care settings. In-depth qualitative interviews and focus groups are only possible with smaller numbers but drawn together they represent a satisfactory sample for the entire PhD study and is an added validation for combining the data in this way to enhance understanding and access in an otherwise difficult to research area.

The use of gatekeepers and gatekeeper organisations was key, especially in the qualitative studies (Papers 2, and 3, Chapters 5 and 6). It is noted that these gatekeepers were known to participants in many instances and so had some history of contact and engagement with participants in case study sites representing a certain inherent bias in recruitment. Careful reflection of gatekeeper roles and interactions with participants was recorded during fieldwork.

#### **8.4.2 Thesis by publication**

Choosing to include peer reviewed publications as chapters for this PhD thesis is worthy of discussion. This approach had a number of strengths. This approach ensures that research findings are disseminated during the four years of the PhD journey rather than at the end. In certain fields such as health care where there are high levels of research activity, timely publication is essential. Developing research skills for publishing throughout the PhD research programme was also a goal for the PhD candidate. The benefit of having undergone regular peer review brought insight and provided feedback which helped strengthen the papers and future publications.

For example, developing a sharper focus in writing, explicating the Irish primary health care system, greater clarity describing methods. It also enhanced critical reflection and learning as well as improved writing skills which aided the write up of this thesis. Furthermore, the publication route supported presentations at national and international conferences. This allowed the PhD candidate to meet a community of experts in the field. The ensuing collaborations and exchange of ideas strengthened the thesis.

Thesis by publication adds to the body of published literature; the literature in this arena is fraught with confusion and misunderstandings. Therefore, contributing to this body of literature across a range of stakeholder perspectives is valuable to an international as well as a national audience and to a number of stakeholders in and across community and primary health care fields.

### **8.4.3 Critical reflection on learning**

A critical aspect of this PhD journey was the need for reflective learning and critical reflection on various aspects of the PhD as they were being undertaken and completed. Core to this was the dual role for the PhD candidate as Senior Researcher employed on three projects and conducting analysis and write up for this purpose and that of PhD student performing data analysis and writing papers for the purposes of answering the PhD question and following the PhD thread. At times these boundaries became blurred (for example, extricating PhD data analysis from project data analysis) and it was important to keep a separate focus on the PhD unit of analysis - community participation on primary care teams. At all times, the PhD

candidate was aware of the need for careful reflection and note taking and the use of separate reflective strategies were helpful e.g., separate research diaries for fieldwork and PhD purposes, the use of critical friends [54, 55], project meetings and PhD supervision meetings to explicate boundaries.

## **8.5 Conclusion**

It is not possible to consider community participation outside a political context [56, 57]. This study has highlighted that there were two political innovations at play in Ireland at the time of this study: the introduction of primary care teams via the primary care strategy and the introduction of community participation via PCTs as a policy vision in this strategy. But this is not enough to guarantee implementation of community participation on PCTs. The problems with full implementation of interdisciplinary team working are not unique to Ireland. However, without a proper PCT structure, community participation is hard to enact. Participants in this study reported that PCTs should be running effectively with adequate vital resources in place before community participation is introduced. The implementation and sustainability of community participation in PCTs in Ireland will be limited unless the functioning of PCTs themselves is stronger and there is greater clarity about the definition of community participation and community representatives' roles on PCTs among all health care professionals. The complex personal and structural barriers to accessing primary healthcare for marginalised groups should be recognised. Evaluative frameworks that capture a range of outcomes should be developed to appraise the processes as well as to provide evidence of the value of the work.

Finally, participation requires a coherence about the work and engagement with both lay and professional experts on a shared terrain, which acknowledges the valid contribution that each can make. This development in turn may require the creation of what may be termed ‘knowledge spaces’ [58, 59] within which both expert knowledge and forms of lay knowledge can interact with each other on an equal basis [60]. Power imbalances which exclude communities from decision-making processes must be acknowledged. Without this level playing field there is a risk that participation initiatives end up consolidating the power of professionals and bureaucrats rather than empowering citizens [61, 62].

## **8.6 Recommendations**

To achieve effective community participation on PCTs:

1. A greater coherence about the meaning of community participation on PCTs should be developed with all stakeholders at the outset of team formation.
2. Stakeholders should share their motivations for getting involved in this work so that their roles and representativeness of team members can be better addressed and understood.
3. Resources to implement PCTs must be in place before community participation on PCTs can be enacted.
4. In implementing the work, a greater understanding of community representatives’ roles and representativeness should be understood by all involved.
5. A greater understanding of the lives of marginalised communities and their needs must be understood by all team members.

6. Policy-makers, practitioners and researchers must consider the potential power imbalances between and within groups in community partnerships, and the broader contextual factors in which participation occurs.
7. Appraisal must address processes as well as outcomes.

### **8.7 Directions for Future Research**

To gain a deeper understanding of the value of the theoretical constructs underpinning community participation described here, a greater level of evidence from studies applying this theory to community participation initiatives from across other international settings is required.

Further research is needed to examine the *experiences* of marginalized populations with their involvement in community participation initiatives, to inform the design of strategies and methods for engaging them in the planning of and decision making for health services.

Future research could investigate how training in methods to enact community participation on PCTs could enable shared understanding to be achieved and clarity of roles to be developed.

Longitudinal research could explore the impact of community participation processes on health outcomes e.g., how increased awareness of services resulting

from community participation initiatives leads to improved health outcomes for a community.

Future evaluations using participatory research methods to explore this topic should be employed to engage communities to design and evaluate strategies and participation methods with marginalized populations to delineate which strategies and methods are appropriate for different marginalized populations and in different contexts

Links between the intangible elements of community participation such as power and the desired outcomes among the community should be explored.

**The final word goes to Morgan, *Participation is alluring and challenging, promising and vexing and necessary and elusive*[63]p. 229**

## **8.8 References**

1. Draper, A.K., G. Hewitt, and S. Rifkin, *Chasing the dragon: developing indicators for the assessment of community participation in health programmes*. Social Sci Med, 2010. **71**.

2. Conklin, A., Z. Morris, and E. Nolte, *What is the evidence base for public involvement in health-care policy?: results of a systematic scoping review*. Health Expectations, 2015. **18**(2): p. 153-165.
3. Kenny, A., et al., *Community participation for rural health: a review of challenges*. Health Expectations, 2015. **18**(6): p. 1906-1917.
4. Bath, J. and J. Wakerman, *Impact of community participation in primary health care: what is the evidence?* Aust J Prim Health, 2013.
5. Kahssay, H.M., P. Oakley, and W.H. Organization, *Community involvement in health development: a review of the concept and practice*, WHO, Editor. 1999: Geneva.
6. Fudge, N., C.D. Wolfe, and C. McKeivitt, *Assessing the promise of user involvement in health service development: ethnographic study*. BMJ, 2008. **336**(7639): p. 313-317.
7. Hogg, C. and C. Williamson, *Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees*. Health Expectations, 2001. **4**(1): p. 2-9.
8. Hogg, C.N., *Patient and public involvement: what next for the NHS?* Health Expectations, 2007. **10**(2): p. 129-138.
9. Neuwelt, P., et al., *Assessing and developing community participation in primary health care in Aotearoa New Zealand: a national study*. New Zeal Med J (Online), 2005. **118**(1218).
10. Zakus, J.D.L. and C.L. Lysack, *Revisiting community participation*. Health Policy and Planning, 1998. **13**(1): p. 1-12.

11. Anderson, E., M. Shepherd, and C. Salisbury, *'Taking off the suit': engaging the community in primary health care decision-making*. Health Expectations, 2006. **9**(1): p. 70-80.
12. Abelson, J., et al., *Deliberations about deliberative methods: issues in the design and evaluation of public participation processes*. Social Science & Medicine, 2003. **57**(2): p. 239-251.
13. Kroneman, M., K. van Erp, and P. Groenewegen, *Community participation in primary care: willingness to participate, a web survey in the Netherlands*. Primary Health Care Research & Development, 2018: p. 1-7.
14. Detmer, D., *Clinician-managers: the 'boundary spanners' of health services*. J Health Serv Res Pol, 2000. **5**: p. 197-198.
15. Taylor, J., et al., *Implementation of oral health initiatives by Australian rural communities: Factors for success*. Health & Social Care in the Community, 2018. **26**(1): p. e102-e110.
16. Taylor, J., et al., *A Role for Communities in Primary Prevention of Chronic Illness? Case Studies in Regional Australia*. Qualitative Health Research, 2013. **23**(8): p. 1103-1113.
17. Taylor, J., et al., *Community and health sector partnerships for primary prevention in Australia: Developing a typology*. Current Sociology, 2012. **60**(4): p. 506-521.
18. Petchey, R., J. Williams, and Y.H. Carter, *From Street-level Bureaucrats to Street-level Policy Entrepreneurs? Central Policy and Local Action in Lottery-funded Community Cancer Care*. Social Policy & Administration, 2008. **42**(1): p. 59-76.

19. Houses of the Oireachtas, *GPs and the Irish Primary Care System: Towards Universal Primary Care?* 2014, Houses of the Oireachtas Dublin.
20. Layte, R., *Projecting the impact of demographic change on the demand for and delivery of healthcare in Ireland.* 2009, Dublin, Ireland: ESRI.
21. O'Sullivan M, W Cullen, and A. MacFarlane, *Primary Care Teams in Ireland: A qualitative mapping review of Irish grey and published literature.* Irish Journal of Medical Science, 2015. 184.1: 69-73.
22. O'Reilly, P., et al., *Assessing the facilitators and barriers of interdisciplinary team working in primary care using normalisation process theory: An integrative review.* PLoS one, 2017. **12**(5): p. e0177026.
23. Sarrami-Foroushani, P., et al., *Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review.* BMC Health Services Research, 2014. **14**(1): p. 402.
24. George, A.S., et al., *Community participation in health systems research: a systematic review assessing the state of research, the nature of interventions involved and the features of engagement with communities.* PLoS One, 2015. **10**(10): p. e0141091.
25. Hoon Chuah, F.L., et al., *Community participation in general health initiatives in high and upper-middle income countries: A systematic review exploring the nature of participation, use of theories, contextual drivers and power relations in community participation.* Social Science & Medicine, 2018. **213**: p. 106-122.
26. Montesanti, S.R., et al., *Enabling the participation of marginalized populations: case studies from a health service organization in Ontario, Canada.* Health Promotion International, 2016. **32**(4): p. 636-649.

27. Nathan, S., L. Johnston, and J. Braithwaite, *The role of community representatives on health service committees: staff expectations vs. reality*. *Health Expectations*, 2011. **14**(3): p. 272-284.
28. Cornwall, A., *Unpacking 'Participation': models, meanings and practices*. *Community Development Journal*, 2008. **43**(3): p. 269-283.
29. Freeman, T., et al., *Service providers' views of community participation at six Australian primary healthcare services: scope for empowerment and challenges to implementation*. *The International Journal of Health Planning and Management*, 2016. **31**(1): p. E1-E21.
30. Hudson, A.L., et al., *Health-seeking challenges among homeless youth*. *Nursing Research*, 2010. **59**(3): p. 212.
31. Edland-Gryt, M. and A.H. Skatvedt, *Thresholds in a low-threshold setting: an empirical study of barriers in a centre for people with drug problems and mental health disorders*. *International Journal of Drug Policy*, 2013. **24**(3): p. 257-264.
32. Wen, C.K., P.L. Hudak, and S.W. Hwang, *Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters*. *Journal of General Internal Medicine*, 2007. **22**(7): p. 1011-1017.
33. Nickasch, B. and S.K. Marnocha, *Healthcare experiences of the homeless*. *Journal of the American Academy of Nurse Practitioners*, 2009. **21**(1): p. 39-46.
34. Asgary, R. and N. Segar, *Barriers to health care access among refugee asylum seekers*. *Journal of Health Care for the Poor and Underserved*, 2011. **22**(2): p. 506-522.

35. Rifkin, S.B., *Lessons from community participation in health programmes*. Health Policy and Planning, 1986. **1**(3): p. 240-249.
36. de Freitas, C. and G. Martin, *Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare*. Social Science & Medicine, 2015. **135**: p. 31-39.
37. Montesanti, S.R., et al., *The value of frameworks as knowledge translation mechanisms to guide community participation practice in Ontario CHCs*. Social Science & Medicine, 2015. **142**: p. 223-231.
38. NICE, *Community Engagement: Improving Health and Wellbeing and Reducing Health Inequalities*. 2016.
39. Preston, R., et al., *Community participation in rural primary health care: intervention or approach?* Aust J Prim Health, 2010. **16**(1): p. 4-16.
40. Tempfer, C.B. and P. Nowak, *Consumer participation and organizational development in health care: a systematic review*. Wiener Klin Wochenschr, 2011. **123**(13-14): p. 408-414.
41. Sarrami-Foroushani, P., et al., *Key concepts in consumer and community engagement: a scoping meta-review*. BMC Health Serv Res, 2014. **14**(1): p. 250.
42. Crawford, M.J., et al., *Systematic review of involving patients in the planning and development of health care*. BMJ, 2002. **325**(7375): p. 1263.
43. Ramsden, V.R., S. McKay, and J. Crowe, *The pursuit of excellence: engaging the community in participatory health research*. Glob Health Promot, 2010. **17**(4): p. 32-42.

44. Attree, P., et al., *The experience of community engagement for individuals: a rapid review of evidence*. Health & Social Care in the Community, 2011. **19**(3): p. 250-260.
45. Milton, B., et al., *The impact of community engagement on health and social outcomes: a systematic review*. Community Development Journal, 2011. **47**(3): p. 316-334.
46. Farmer, J., et al., *Citizen participation in health services co-production: a roadmap for navigating participation types and outcomes*. Aust J Prim Health, 2018. **23**(6): p. 509-515.
47. Janamian, T., L. Crossland, and L. Wells, *On the road to value co-creation in health care: the role of consumers in defining the destination, planning the journey and sharing the drive*. The Medical Journal of Australia, 2016. **204**(7): p. 12.
48. May, C. and T. Finch, *Implementing, embedding, and integrating practices: An outline of Normalization Process Theory*. Sociology, 2009. **43**(3): p. 535-554.
49. Taylor, J., D. Wilkinson, and B. Cheers, *Is it consumer or community participation? Examining the links between 'community' and 'participation'*. Health Sociology Review, 2006. **15**(1): p. 38-47.
50. Gillespie, B.M., et al., *Using normalisation process theory to evaluate the implementation of a complex intervention to embed the surgical safety checklist*. BMC Health Services Research, 2018. **18**(1): p. 170.
51. Eccles, M., et al., *An implementation research agenda*. Implement Sci, 2009. **4**(1): p. 18.

52. McEvoy, R., et al., *A qualitative systematic review of studies using the normalization process theory to research implementation processes*. *Implement Sci*, 2014. **9**(2).
53. Johnson, R.B. and A.J. Onwuegbuzie, *Mixed methods research: A research paradigm whose time has come*. *Educational Researcher*, 2004. **33**(7): p. 14-26.
54. Foulger, T.S., *External Conversations: An unexpected discovery about the critical friend in action research inquiries*. *Action Research*, 2009. **8**(2): p. 135-152.
55. Deuchar, R., *Facilitator, director or critical friend?: contradiction and congruence in doctoral supervision styles*. *Teaching in Higher Education*, 2008. **13**(4): p. 489-500.
56. Rifkin, S.B., *Lessons from community participation in health programmes: a review of the post Alma-Ata experience*. *Int Health*, 2009. **1**(1): p. 31-36.
57. Beresford, P., *User Involvement in Research and Evaluation: Liberation or Regulation?* *Social Policy and Society*, 2002. **1**(02): p. 95-105.
58. Elliott, E. and G. Williams, *Developing public sociology through health impact assessment*. *Sociology of Health & Illness*, 2008. **30**(7): p. 1101-1116.
59. Jasanoff, S., *Designs on nature: Science and democracy in Europe and the United States*. 2011: Princeton University Press.
60. Gibson, A., N. Britten, and J. Lynch, *Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement*. *Health*, 2012. **16**(5): p. 531-547.

61. Charles, C. and S. DeMaio, *Lay participation in health care decision making: a conceptual framework*. Journal of Health Politics, Policy and Law, 1993. **18**(4): p. 881-904.
62. Morone, J.A., *The democratic wish: Popular participation and the limits of American government*. 1998: Yale University Press.
63. Morgan, L.M., *Community participation in health: perpetual allure, persistent challenge*. Health Policy and Planning, 2001. **16**(3): p. 221-230.

## Appendices

### Appendix 1: Rationale for Journal Selection and Copyright of Papers

Careful consideration was given to the type of Journal that would best resonate with the aims, objectives, content and intended target audience of each of the three research papers which comprise this PhD.

Hence the three journals selected were based on their attention to community participation, primary health care and interdisciplinary team working in primary care. Consideration was also given to the topic of implementation research and the need to speak to a wide audience interested in health policy as well as primary healthcare context and service user involvement and participation in health care systems.

#### **BMC Family Medicine: Paper 1**

*BMC Family Practice* is an open access, peer-reviewed journal that considers articles on all aspects of primary health care, including clinical management of patients, professional training, shared decision making, and the organisation and evaluation of health care in the community.

It was selected because of its focus on primary healthcare research and its target audience of researchers, academics and practitioners (i.e. nurses, GPs, health service managers, local groups in community health), thus bridging the gap between the two areas. And its relevance to implementation of primary health care policy. The paper

about implementation of primary care policy and health professional views of implementation of PCTs was deemed suitable for this target audience.

All articles published by *BMC Family Practice* are made freely and permanently accessible online immediately upon publication, without subscription charges or registration barriers. *BMC Family Practice* has an Impact Factor of 1.641. *BMC Family Practice's* open access policy allows maximum visibility of articles published in the journal as they are available to a wide, global audience.

### **Health Expectations: Paper 2**

I chose this journal because firstly *Health Expectations* promotes critical thinking and informed debate about all aspects of public participation in health care and health policy, including methods for monitoring and evaluating participation.

*Secondly, Health Expectations* is a quarterly, peer-reviewed journal which publishes original research, review articles and critical commentaries. It includes papers which clarify concepts, develop theories, and critically analyse and evaluate specific policies and practices. Therefore, I believe my paper about the implementation of community participation on primary care teams in an Irish context was particularly suitable. Furthermore, it provides a multi-disciplinary and international forum in which researchers from a variety of backgrounds can present their work to other researchers, policy makers, health care professionals, managers and consumer advocates making my paper of a theoretically informed multi perspectival analysis of implementation of community participation on primary care teams particularly relevant for readers. Finally, it has an impact Factor of 3.207 and a five-year Impact factor 3.752 giving it a wide readership which can enhance and promote my research. It also has the following ISI Journal Citation Reports © Ranking: 2015:

4/74 (Health Policy & Services); 13/87 (Health Care Sciences & Services); 28/172 (Public Environmental & Occupational Health).

### **International Journal for Equity in Health: Paper 3**

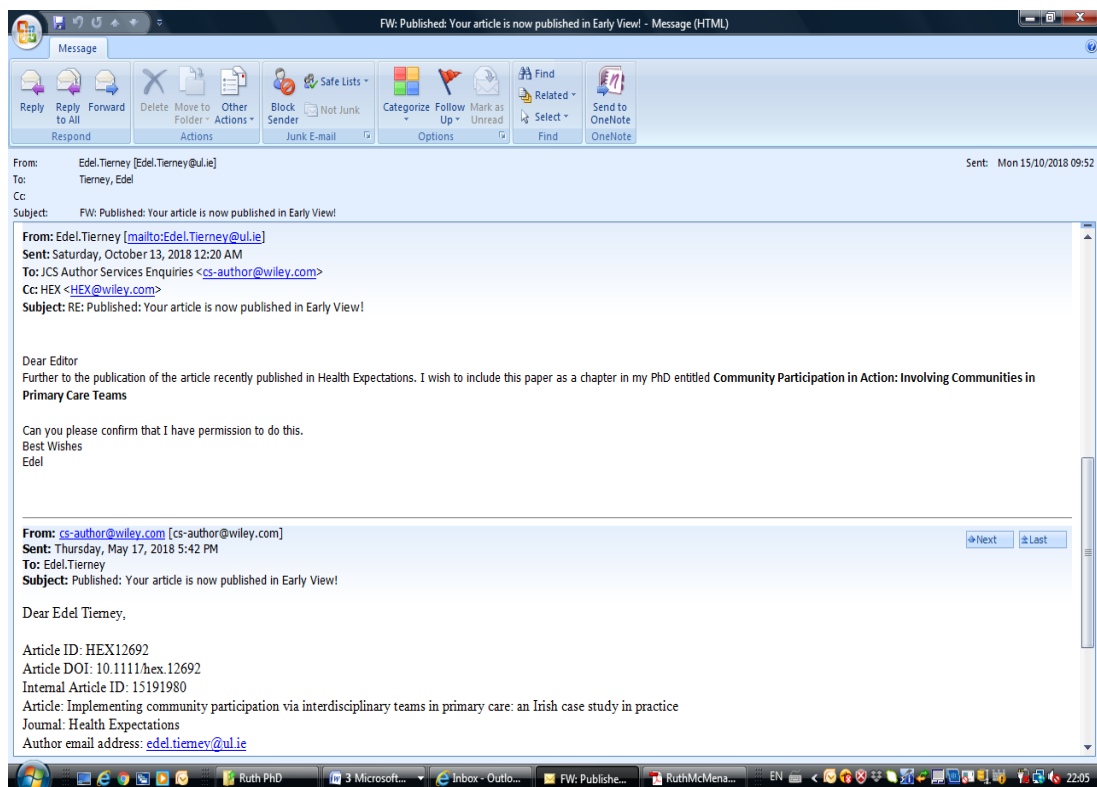
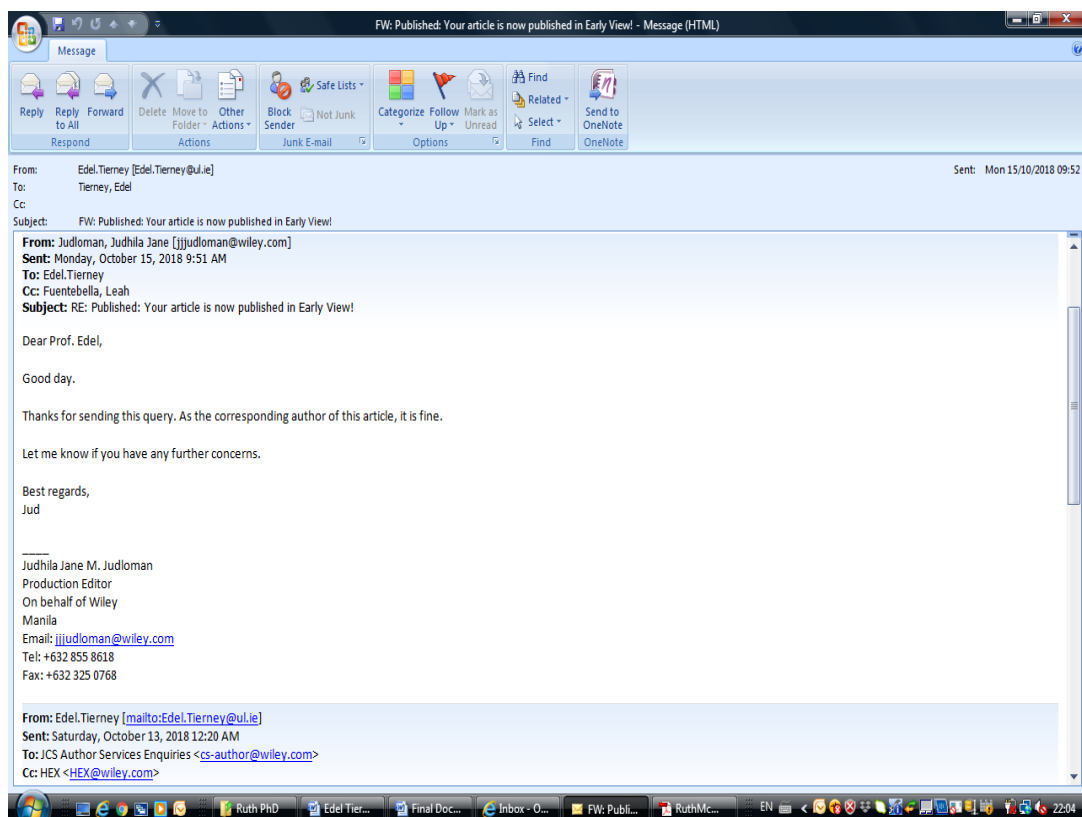
This journal presents evidence relevant to the search for, and attainment of, equity in health across and within countries. The journal publishes research which improves the understanding of issues that influence the health of populations. This includes the discussion of political, policy-related, economic, social and health services-related influences. Although there is a large amount of literature on the 'social determinants' of health, this journal focuses heavily on influences at the individual, at the community level. The literature is relatively sparse on influences in the policy and political arenas and is especially deficient in analyses that examine the population-attributable fraction of ill health resulting from the different categories of influences. Such information is required by policy-makers in order to make informed choices and evidence-based decisions.

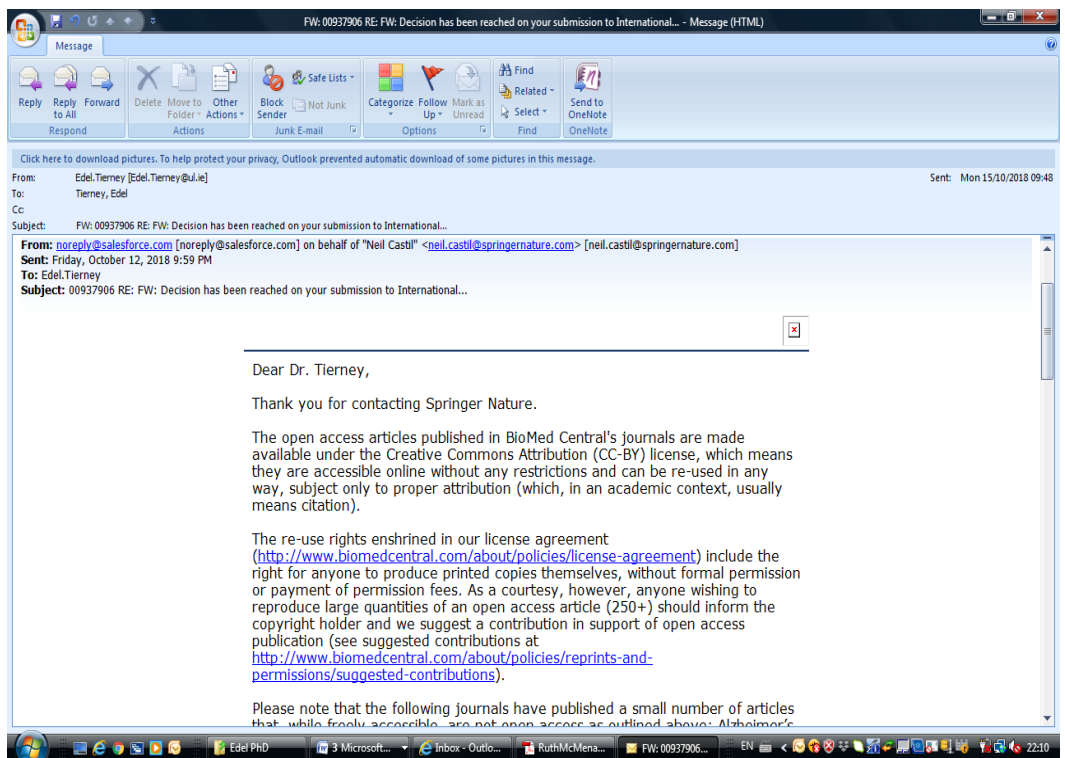
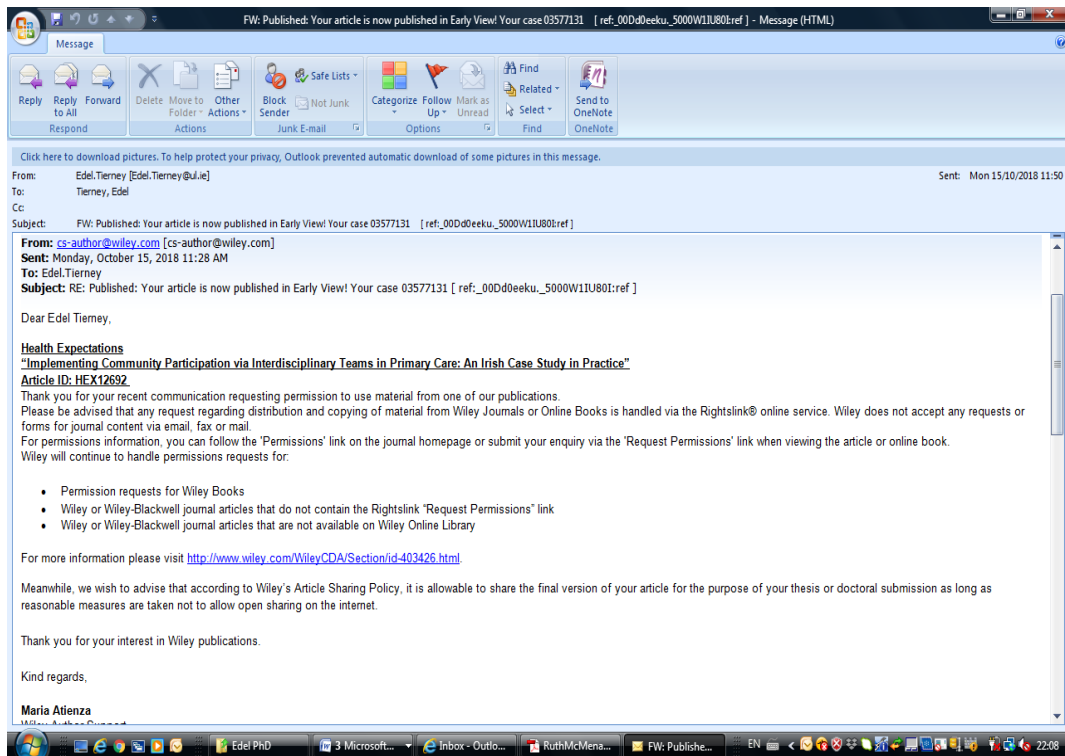
This paper about priority setting for primary care by marginalized groups was deemed relevant across individual and collective participation levels as well as socio-political and policy implementation levels. The data presented in this paper is of interest to an international as well as a national primary care audience.

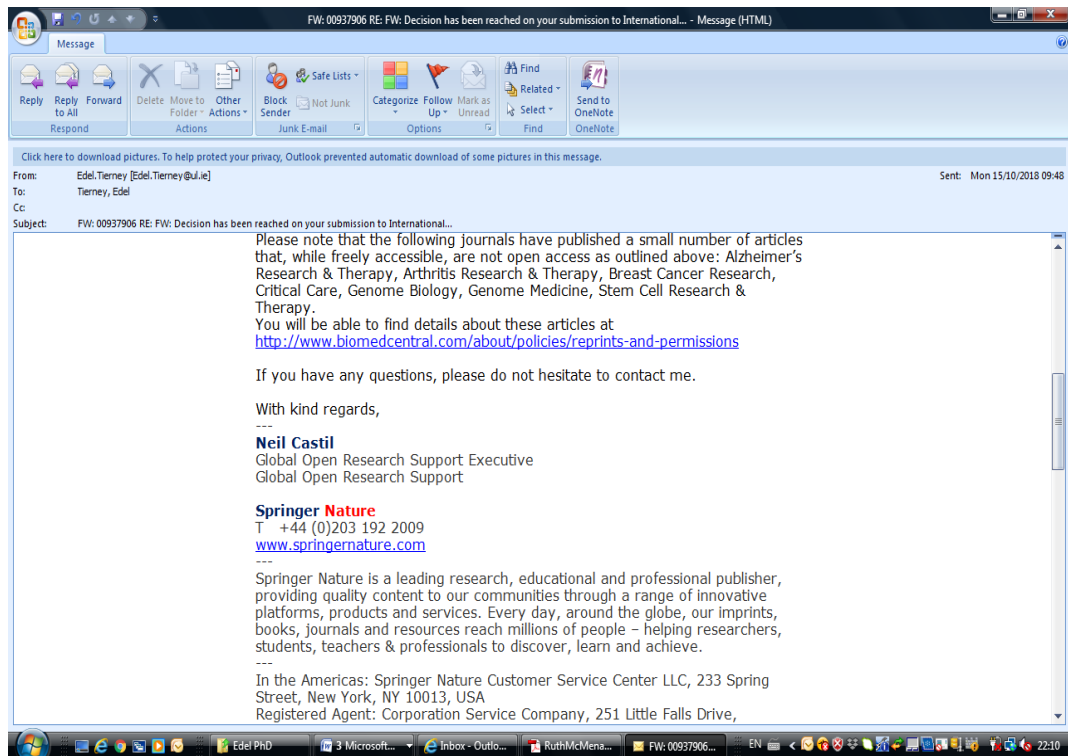
All articles published by *International Journal for Equity in Health* are made freely and permanently accessible online immediately upon publication, without subscription charges or registration barriers. *International Journal for Equity in Health* has an Impact Factor of 2.378.

<http://equityhealthj.biomedcentral.com/>

## Copyright Permissions for Published Papers







Reprints and permissions BMC Family Medicine.htm

**Appendix 2: Examples of deliberative democracy methods which have been applied to primary health care across international settings**

| Country                         | Policy and Year  | Methods to Enact Community Participation  |
|---------------------------------|--|---|
| Australia                       | Community Participation in Primary Care embedded in Policy<br>Department of Health, <i>National Primary Health Care Strategic Framework</i> 2013 [1]   | Medicare locals [2]<br>Citizen juries [3]<br>Community Representatives on Health Service Committees [4]   |
| New Zealand                     | Community Participation in Primary Health Care Organisations embedded in New Zealand's Primary Health Care Strategy [5] and in Primary Health Organisations (PHOs)<br><i>The Primary Health Care Strategy</i> 2001 [5]   | Community Participation in PHOs [5, 6]  |
| Canada                          | Community Participation in Primary Care embedded in Policy<br>Health Council of Canada, <i>Teams in Action Primary Health Care Teams for Canadians</i> 2009 [7]  | Community needs analysis [7]<br>Consultations with community [7]<br>Dialogue sessions [8]   |
| Netherlands                     | No evidence of Community Participation in Primary Care embedded in Policy<br>Not Available   | Patient representatives [9]<br>Patient representatives via patient organisations Neo-Corporatist Model [10]   |
| UK: England, Scotland and Wales | Community Participation in Primary Care embedded in Policy in England [11-14]<br>Department of Health, <i>Involving patients and the public in healthcare: response to the listening exercise</i> , Department of Health 2001[13]<br>Department of Health, <i>The NHS Plan</i> 2000 [11]<br><br>Department of Health, <i>Patient and public involvement in the NHS</i> 1999, | Citizens Jury [3, 18]<br>Lay Representatives on primary care Trusts e.g., Healthy Living Centre [19]<br>Patient Participation Groups (PPGs) [15-17, 20-23]<br>Patient Reference Groups [24]<br>Critical Friends Group [25]<br>Clinical Commissioning Groups (CCGs) [26] |

| Country | Policy and Year   | Methods to Enact Community Participation   |
|---------|---|--|
|         | Department of Health, <i>Department of Health; NHS and Social Care Act 2012</i> [83-85]<br>Welsh Government, <i>Parliamentary Review of Health and Social Care in Wales Interim Report 2017</i><br>Welsh Government, <i>Our plan for a primary care service for Wales up to March 2018</i> 2014, Welsh Government [15, 16]<br>Scottish Health Council, <i>Promoting, supporting and developing public involvement in primary care</i> 2013 [17] |  |
| Italy   | National government launched the third reform of the health-care system in 1999 (Legislative Decree n. 229/99).   | Mixed Advisory Committee (MACs) [27]   |
| Ireland | Community participation in primary health care is embedded in health policy - Primary Care Strategy<br><br>Department of Health and Children, <i>Primary Care: A New Direction</i> . 2001 [28]  | Community Participation on Primary Care Teams (PCTs) [28]  |
| Belgium | Belgian health care system is based on the 1963 Health Insurance and Hospital Acts.<br>The management of primary care in Belgium is mostly at the federal level [29, 30]  | Community Oriented Primary Care (COPC) involving the local community in a continuous process of information gathering, including the design of health-need assessments, planning, and intervention and monitoring of local outcomes[31-33] |

## References:

1. Department of Health, *National Primary Health Care Strategic Framework* Commonwealth State and Territory Health Departments, Editor. 2013: Sydney, Australia.
2. Department of Health and Ageing, *Building a 21st Century Primary Health Care System: A Draft of Australia's First National Primary Health Care Strategy*. 2009, Commonwealth of Australia: Canberra
3. Bath, J. and J. Wakerman, *Impact of community participation in primary health care: what is the evidence?* Aust J Prim Health, 2013.
4. Nathan, S., L. Johnston, and J. Braithwaite, *The role of community representatives on health service committees: staff expectations vs. reality*. Health Expectations, 2011. **14**(3): p. 272-284.
5. King, H.A., *The primary health care strategy*. 2001, Ministry of Health: Wellington.
6. Neuwelt, P., et al., *Assessing and developing community participation in primary health care in Aotearoa New Zealand: a national study*. New Zeal Med J (Online), 2005. **118**(1218).
7. Health Council of Canada, *Teams in Action Primary Health Care Teams for Canadians*. 2009, Health Council of Canada: Toronto
8. Maxwell, J., S. Rosell, and P.-G. Forest, *Giving citizens a voice in healthcare policy in Canada*. BMJ: British Medical Journal, 2003. **326**(7397): p. 1031.
9. Kroneman, M., K. van Erp, and P. Groenewegen, *Community participation in primary care: willingness to participate, a web survey in the Netherlands*. Primary Health Care Research & Development, 2018: p. 1-7.

10. Van de Bovenkamp, H.M., M.J. Trappenburg, and K.J. Grit, *Patient participation in collective healthcare decision making: the Dutch model*. Health Expect, 2010. **13**(1): p. 73-85.
11. Department of Health, *The NHS Plan*. 2000, HMSO: London.
12. Department of Health, *Patient and public involvement in the NHS 1999*, UK Department of Health: London.
13. Department of Health, *Involving patients and the public in healthcare: response to the listening exercise*, Department of Health, Editor. 2001, UK Department of Health: London.
14. Department of Health, *Department of Health; NHS and Social Care Act*, Department of Health, Editor. 2001, HMSO: London.
15. Welsh Government, *Our plan for a primary care service for Wales up to March 2018*. 2014, Welsh Government.
16. Welsh Government, *Parliamentary Review of Health and Social Care in Wales Interim Report*. 2017, Welsh Government.
17. Scottish Health Council, *Promoting, supporting and developing public involvement in primary care 2013*, The Scottish Health Council.
18. Gooberman-Hill, R., J. Horwood, and M. Calnan, *Citizens' juries in planning research priorities: process, engagement and outcome*. Health Expect., 2008. **11**(3): p. 272-281.
19. Anderson, E., M. Shepherd, and C. Salisbury, *'Taking off the suit': engaging the community in primary health care decision-making*. Health Expect, 2006. **9**(1): p. 70-80.
20. Brown, I., *Patient participation groups in general practice in the National Health Service*. Health Expect, 1999. **2**(3): p. 169-178.

21. Wilkie, P., *Patient participation groups in general practice: building better partnerships*. 2016, Brit Gen Pract. p. 548-549.
22. Box, G., *Patient participation groups: the national picture*. Quality in Primary Care, 2009. **17**(4): p. 291-297.
23. Gillam, S. and J. Newbould, *Patient participation groups in general practice: what are they for, where are they going?* BMJ, 2016. **352**.
24. Pollard, L., et al., *The impact of patient participation direct enhanced service on patient reference groups in primary care: a qualitative study*. Quality in Primary Care, 2014. **22**(4): p. 189-199.
25. Greco, M., et al., *Impact of patient involvement in general practice*. Education for Primary Care, 2006. **17**(5).
26. O'Shea, A., M. Chambers, and A. Boaz, *Whose voices? Patient and public involvement in clinical commissioning*. Health Expect, 2016. **20**: p. 484-494.
27. Serapioni, M. and N. Duxbury, *Citizens' participation in the Italian health-care system: the experience of the Mixed Advisory Committees*. Health Expect, 2014. **17**(4): p. 488-499.
28. Department of Health and Children, *Primary Care: A New Direction*. 2001, Department of Health and Children: Dublin.
29. Gezondheidsraad, V., *De toekomst van het gezondheids (zorg) beleid in Vlaanderen, met bijzondere aandacht voor de eerstelijnsgezondheidszorg*. Gedownload op, 2006. **5**.
30. Kringos, D.S., et al., *Building primary care in a changing Europe. Case studies*. 2015: WHO Regional Office for Europe.

31. Rawaf, S., J. De Maeseneer, and B. Starfield, *From Alma-Ata to Almaty: a new start for primary health care*. The Lancet, 2008. **372**(9647): p. 1365-1367.
32. Rhyne, R., et al., *Community Oriented Primary Care: health care for the 21st century*. 1998.
33. Art, B., et al., *An interdisciplinary community diagnosis experience in an undergraduate medical curriculum: development at Ghent University*. Academic Medicine, 2008. **83**(7): p. 675-683.

## Appendix 3a: Ethical approval for each of the three projects

### Project 1: Towards a Framework for Implementation of Community Participation in Primary Care

1<sup>st</sup> December 2010

Dr. Anne MacFarlane  
Lecturer in Primary Care  
Discipline of General Practice  
1 Distillery Road  
NUI  
Galway

**Re: User involvement in primary healthcare: Toward a framework for implementation.**

Dear Dr. MacFarlane,

I wish to confirm that the above study was reviewed by the Research Ethics Committee on 24<sup>th</sup> November, 2010. The committee agreed to approve the recruitment part of this study only at this time i.e. the selection of the five sites. The committee were of the view that they could not approve the study in full without knowledge of the five sites, the nature of the client groups at each site and the methods of recruitment and obtaining informed consent from participants at these sites.

Once the five sites have been identified you are asked to re-submit to the committee taking into consideration any specific requirements for the individual sites particularly around the recruitment and consenting of respondents at each site. The committee were particularly concerned about the recruiting and consenting of services users at the sites. Letters of support will also have to be submitted from the 'gate keepers' of these sites.

If you have any queries please contact Ms. Pauline Tierney – [pauline.tierney@icgp.ie](mailto:pauline.tierney@icgp.ie)

Yours sincerely,

---

Prof. Colin Bradley  
Chair Research Ethics Committee

17th September 2012

Prof Anne McFarlane

Graduate Entry Medical School

University of Limerick

Limerick

**FUSION - Towards a Framework for Implementation of User Involvement in  
Primary Care**

Dear Prof McFarlane,

I wish to confirm that on review of your amended material re the FUSION project it is now somewhat clearer with regard to what will happen to research participants.

The consent form is also now quite clear. With regard to photographs, there is still a bit of a problem because, while participants are assured their confidentiality will not be breached, this is not possible if photographs of participants are taken and displayed in public fora. Photographs are intrinsically very identifying and displaying of a photograph constitutes a considerable risk to the confidentiality of a participant. There is an option on the consent form for the taking of photographs of participants but there is no mention of this in the participant information (revised).

We would suggest that the matter of taking of photographs of participants ought to be the subject of an additional and separate consenting process in which participants would be given relevant information in an information sheet and then be asked to sign a separate consent form in relation to the taking of their photograph. The information sheet would need to say why a photograph might be needed, the use(s)

to which the photograph would be put and highlight the fact that their appearance in a photograph might allow a participant to be identified and, hence, potentially undermine, to some extent, the confidentiality of which they have otherwise been assured. Other factors which lessen the risks associated with this, such as the aggregate nature of data that might be presented and the fact that presentations would be exclusively to scientific meetings and the like, may, of course, also be highlighted. Incidentally, whether any meetings at which findings would be presented and, therefore, photographs might be shown are open to the general media or closed to the media would also be a matter of concern that ought to be considered.

Thus, I am agreeable to approving the project with the amended material excluding the taking of photographs. This will only be approved subject to our satisfaction that there is an appropriate additional information provision and consent procedure relating specifically to this issue.

If you have any queries please contact - [janet.stafford@icgp.ie](mailto:janet.stafford@icgp.ie)

Yours Sincerely

-----

Prof Colin Bradley

Chair Research Ethics Committee

**Project 2: Primary Care Reform in Ireland: An Exploration of  
Interdisciplinary Team Working: Levers and Barriers to Implementation**



29<sup>th</sup> November, 2013

Professor Anne Mac Farlane  
Graduate Entry Medical School,  
University of Limerick,  
Limerick

**Primary Care Reform in Ireland – An analysis of ‘top down’ and ‘bottom up’  
innovation**

Dear Professor Mac Farlane,

I wish to confirm that the above application was reviewed by the Research Ethics Committee on 20<sup>th</sup> November, 2013. The committee will approve the study subject to the following clarification:

- WPI: Request to see copy of the survey instrument.

If you have any queries please contact Sally-Anne O’Neill – [sallyanne.o'neill@icgp.ie](mailto:sallyanne.o'neill@icgp.ie)

Yours sincerely,

**Professor Colin Bradley**  
**Chair Research Ethics Committee**

## Project 3: Exploring Levers and Barriers to Accessing Primary Care for Marginalised Groups



4<sup>th</sup> June, 2014

Professor Anne Mac Farlane,  
Professor of Primary Healthcare Research,  
Graduate Entry Medical School,  
University of Limerick,  
Castletroy,  
Limerick

**Improving access to primary care services for marginalised communities**

Dear Professor Mac Farlane,

I wish to confirm that I have reviewed the clarifications for the above named study and am now happy to approve this study.

If you have any queries please contact Sally-Anne O'Neill – [sallyanne.o'neill@icgp.ie](mailto:sallyanne.o'neill@icgp.ie)

Yours sincerely,

**Professor Colin Bradley**  
Chair Research Ethics Committee

## Appendix 3b: Ethical approval for use of photographs in PLA sessions (Paper 2

### Chapter 5)

**From:** Bradley, Colin <[C.Bradley@ucc.ie](mailto:C.Bradley@ucc.ie)>  
**Sent:** Thursday 29 November 2012 13:31  
**To:** Tierney, Edel <[edel.tierney@nuigalway.ie](mailto:edel.tierney@nuigalway.ie)>  
**Cc:** Anne.MacFarlane <[Anne.MacFarlane@ul.ie](mailto:Anne.MacFarlane@ul.ie)>; [janet.stafford@icgp.ie](mailto:janet.stafford@icgp.ie)  
**Subject:** RE: FUSION amendments to information sheets and consent forms

Hi Edel

I've reviewed the revised consent form and information regarding the use of photographic images. I am now happy to approve this project

Colin

From the desk of Professor Colin P Bradley,  
Professor and Head of Department of General Practice  
Department of General Practice  
Room G.52 Western Gateway Building  
University College Cork  
Western Road  
Cork  
IRELAND

Tel + 353 (0) 21 4901572  
Department e-mail [gp@ucc.ie](mailto:gp@ucc.ie)

**From:** Tierney, Edel [<mailto:edel.tierney@nuigalway.ie>]  
**Sent:** 26 November 2012 14:36  
**To:** Bradley, Colin  
**Cc:** Anne.MacFarlane; [janet.stafford@icgp.ie](mailto:janet.stafford@icgp.ie)  
**Subject:** FUSION amendments to information sheets and consent forms

Dear Prof Bradley,

I am writing on behalf of Prof Anne MacFarlane PI on the HRB funded project **FUSION - Towards a Framework for Implementation of User Involvement in Primary Care.**

Further to your correspondence in August 2012 re FUSION information leaflets and the use of photographs in this project, please find attached amended information leaflets for participants; service users and service providers and consent forms as per your recommendations.

As you can see we have taken out all reference to the photographs in general information leaflets and consent form and have created separate information leaflet and consent form which deal specifically with the use of photographs for the purpose of the study.

I hope that these amendments meet with your approval and we look forward to hearing from you in due course.

Kind Regards

Edel

Edel Tierney  
Senior Researcher FUSION project  
Primary Healthcare Research Group  
Graduate Entry Medical School University of Limerick  
Located at  
Discipline of General Practice and Primary Care  
School of Medicine  
NUI Galway  
Phone: 091 495193  
[email:edel.tierney@nuigalway.ie](mailto:edel.tierney@nuigalway.ie)

**Appendix 4: Examples of analytical notes from fieldwork**

**Researchers Debriefing Notes Following Focus Group with Homeless**

**Participants Paper 3:**

**DEBRIEFING FIELDWORK - GUIDELINE**

*NAME: Location in City FGI POD, ET, COR*

**1. Please describe the participants with whom you worked.**

- *SERVICE NAME Residents: 4 males, 2 females- K T C N & E*
- *Research Team: POD, ET, COR*

**2. What was the topic?**

*Access to Primary Health Care in the Community.*

**3. What PLA technique did you choose to match this topic?**

*Flexible Brainstorm*

**4. Please attach completed RECORDING FORM and any NOTES to this form.**

*Flexible brainstorm chart*

**5. How long did your fieldwork take?**

*2.5 hours*

**6. What was your best learning from the fieldwork experience?**

- *6 very vocal participants on reflection may have been too many participants, 5 is probably the most beneficial number in terms of information and allowing each participant to feel heard.*
- *Learning how to facilitate less vocal people while also not putting too much pressure on less vocal people to feel pressurised into contributing. There was one very vocal person and one very quiet person in the group and this was difficult to maintain balance.*
- *Not allowing more dominant people to take over the group.*
- *The label “homeless” did not come up during our focus group session- Should we have brought it up? (for discussion with AMacF)*
- *This specific group had complex health issues.*
- *In the main, drug use, rehabilitation programmes, mental health and associated problems were the main topics under discussion.*
- *There were a number of positive experiences vocalised – GP since childhood a long-term relationship, Psychiatrist who “saved my life” and all of the group spoke of being grateful for SERVICENAME and 5 of the*

participants spoke positively about their experience with *SERVICENAME* house.

**7. What do you think was the best learning for your participant(s)?**

- Participants reported being listened to and feeling heard. \*NB\*
- They appeared to enjoy it although they were suspicious at first, but felt comfortable telling us about their reservations by the end of the session
- They reported that they now realised their experiences were more similar than dissimilar e.g., they reported similar experiences of anxiety, life experiences, methadone programmes, and self-medication.
- They talked about the issue of trust and how they now had trust in the research team.
- The group were very supportive of one another during the session all reported that they enjoyed the group and ‘got something from it’

**8. What key information was shared/generated during your fieldwork encounter? (Please feel free to attach a separate sheet if you do not have sufficient room to make your remarks in this space.)**

- The **high prevalence of anxiety** and its destructive nature was a key theme throughout the session.
- The participants found managing anxiety difficult often resulting in **self-management** with prescribed and street medication.
- Another key theme was the feeling that doctors “did not listen” and that they felt their **needs outside of their methadone treatment/ drug addiction were not being met** in primary care.
- The participants shared that they felt the current **prescription charges** had had a big impact on people and felt this was having a negative impact on the management of people’s healthcare needs.
- The participants felt that healthcare would be very **expensive** without a medical card. However, they did find the medical card to be restrictive in certain areas e.g. Dental care and they found that the medical card alone did not meet all their current needs.
- Medical card often restricted their access to particular health professionals. Not all accept the medical card
- The participants expressed a desire to “**live a life**” and not just exist.
- Participants spoke about the positive support which they get from *SERVICE NAME* ....

**9. What, if anything, would you do differently next time round?**

- Should we mention the idea of/ the concept of “being homeless”?
- Should we make a more clear differentiation between those who are homeless and those who are drug users?- perhaps Prof Anne McFarlane /Austin O’Carroll may be helpful in helping answer this question?
- ET will email AMF for advice before the next focus group.

- *A maximum of 5 participants in future groups if possible*
- *Bring Fruit!*
- *Definitely stick with the 2 sessions rather than try and get as much out of them as possible in 1 session*
- *Continue to stick to time schedule and end on time.*

***10. Were there any particular issues which arose for you or the participants which you feel requires follow up or referral for further support?***

*E discussions with E Re - benzo withdrawal. POD will follow up*

# JOURNAL NOTE

## **POD:**

Negotiating roles as a GP and researcher, and exploring his comfort in managing the two roles during the group sessions. I think it is becoming easier for me to divide my mind when approaching the two types of work. It was made easier by the fact that none of the participants had actually been patients in the clinic so far. I was also eager not to do any 'house-call' work location day of the FG, to help me separate the roles.

Also the issue of identifying POD as "the doctor location" – came up in conversation regarding what services are available & I said it was me running the service, the participants seemed happy about the service and that we were researching further issues around access. I thought for a split second about not saying anything, not 'admitting' it was me running the clinic, but that would be dishonest & could lead to breakdown in trust with participants if discovered. I was slightly embarrassed at the complements on the service, but also proud that it seemed to make a difference & had been talked about among the people it was designed for.

I was a little uncomfortable at the mention of local GPs names during the FG, it was mostly where they had clashed with the participant on an issue. Sometimes this sounded justified, other times it sounded like they were being rude.

At times I was very embarrassed at the way the participants said they had been treated by GP colleagues- the 'junkie' label was mentioned by one GP

This was balanced with some stories of GP treating clients firmly but with respect & kindness, and that made me happy

## **COR:**

During this particular session, the GP's mentioned were not personal close contacts nor were they GP's I have a personal relationship with, which allowed me to have a bit of distance from the criticism.

However, I did feel ashamed, as a GP, at the perceived poor treatment and the stigmatisation the participants had felt secondary to their addictions.

Personally, the criticism has provided me with a good inside view of how important it is to treat my patients at all times with dignity and respect.

It also allowed me to see how multifactorial the patient's problems are and how it's important to address the most pertinent issue in the patient's life at each consultation and at each consultation, rather than labelling them with one specific diagnosis and then never moving on from this one issue.

**ET:** Introducing the idea/ concept of homelessness.

I was struck during reflection about the lack of discussion about homelessness. I reflected that unlike the 'migrant group' who identified their health care experiences as a migrant this group did not mention the issue of homelessness.

They identified with their use of drugs and their access to rehabilitation programmes, methadone programmes, health issues related to their drug use anxiety depression etc.

I wondered if I should bring the issue of homelessness into the discussion or if it is sufficient that they have answered the question asked.

I have emailed AMF for her advice about this.

**Researcher Debriefing Notes Following Interview with Participant Paper 2  
Chapter 5:**

**DEBRIEFING: Interview with Participant  
Primary Care Development Officer**

NAME: Edel Tierney

Interview

|   |
|---|
| <p><b>11. Please describe the participants with whom you worked.</b><br/>I interviewed _____ Primary Care Development Officer</p>   |
| <p><b>12. What was the topic?</b><br/>The topic was SUI in Primary Care teams. NAME spoke about his experience of working with NAME OF Community Health forum and the general topic of community participation.<br/>NAME spoke about his role, how he got involved, the more general policy context and HSE context of Community participation.</p>   |
| <p><b>13. What PLA technique did you choose to match this topic?</b><br/>I conducted a one to one interview with NAME with lap top as a prop with the four questions.</p>   |
| <p><b>14. Please attach completed RECORDING FORM and any NOTES to this form.</b><br/>Reflection chart completed and interview transcript.</p>   |
| <p><b>15. How long did your fieldwork take?</b><br/>Approx. one hour. The recorded interview was approx. 27 minutes.</p>  |
| <p><b>16. What was your best learning from the fieldwork experience?</b><br/>My best learning from this interview was that it is good to allow time before and after the interview for a bit of chit chat. -----was not aware of the project or its origins and was surprised about its existence.<br/>He asked me if TDO from the HSE knew of its existence and felt that it would be important that he would be informed about this.<br/>-----asked me about the funding for the project and I could not remember the exact amount. I need to know this when going in to interview somebody.</p>                      |
| <p><b>17. What do you think was the best learning for your participant(s)?</b><br/>I think that -----has a keen interest in this topic and was very interested in the project. He was very keen that information be shared within the HSE about this project. He was most interested in how the sites were chosen and who the participants' were for interviews and focus groups. He was very interested in the fact that I was speaking with community representatives.</p>  |
| <p><b>18. What key information was shared/generated during your fieldwork encounter?</b><br/>Key information was shared about the project and its proposed outcomes. I clarified how this may be able to add to the draft strategy on user involvement in place.<br/>-----shared a lot of information with me about the policy context and the need for HSE commitment to this topic and buy-in at management level.<br/>I need to have more information about precise funding available to me if I am asked so that I can answer this honestly. I don't want it to appear that I am trying to fudge this question.</p> |
| <p><b>19. What, if anything, would you do differently next time round?</b><br/>I think the interview worked well and that I was well prepared. I would not change anything except that I would have information on funding available next time.</p>   |

**Appendix 5: Alternative theories considered to be relevant to implementation of community participation on PCTs**

| <b>Theory</b>   | <b>Description of theory</b>   |
|---|--|
| <b>Diffusions of innovation theory [1]</b>  | <p>Considered the single most influential theory in the broader field of knowledge utilisation. Seeks to explain how, why, and at what rate new ideas and technology spread through cultures. Describes how individuals within an organisation receive, adopt and adapt evidence, the organisational factors that impede or facilitate the adoption or implementation of the evidence and other factors within organisations that influence responses to the policy issues.</p> <p>Widely applied in implementation science to assess the extent to which the characteristics of the implementation object (e.g., clinical guidelines) affect implementation outcomes. Highlights the importance of intermediary actors (opinion leaders, change agents and gatekeepers) for successful adoption and implementation.</p> |
| <b>COM-B (Capability, Opportunity, Motivation and Behaviour) [2]</b>                    | <p>This theory identifies motivation as a process that energises and directs behaviour. Capability and opportunity are necessary conditions for a behaviour to occur, given sufficient motivation. Capability opportunity and motivation generate behaviour which in turn influences the three components. Opportunity and capability can influence motivation, which enacting a behaviour can alter capability motivation and opportunity.</p>  |
| <b>Theoretical Domains framework [3]</b>  | <p>A framework, grounded in psychological theory, that is useful to (and usable by) researchers working with health service managers towards implementation of Evidence Based Practice (EBP).</p> <p>Outlines 12 theoretical domains which should be considered when seeking explanations of failure to implement EBP and/or designing interventions to achieve improved implementation.</p>   |
| <b>Theory of Planned Behaviour [4]</b>  | <p>A theory about the link between beliefs and behaviour, and can explain the individuals social behaviour by considering the social norm as an important variable.</p>  |
| <b>Reach, Efficacy, Adoption, Implementation and Maintenance Framework (RE-AIM) [5]</b> | <p>A model for evaluating public health interventions on 5 dimensions: for reach, efficacy, adoption, implementation, and maintenance. These dimensions occur at multiple levels (e.g., individual, clinic or organisation, community) and interact to determine the public health or population-based impact of a programme or policy. Evaluating each of these dimensions and combining them can determine overall public health impact.</p>   |

| Theory  | Description of theory   |
|---|---|
| Consolidated Framework for Implementation Research (CFIR) [6] | A framework which offers an overarching typology to promote implementation theory development and verification about what works where and why across multiple contexts. The CFIR is composed of five major domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation. It can be used to guide formative evaluations and build the implementation knowledge base across multiple studies and settings. |

### References:

1. Rogers, E.M., *Diffusion of innovations*. 2010: Simon and Schuster.
2. Michie, S., L. Atkins, and R. West, *The behaviour change wheel: a guide to designing interventions*. Needed: physician leaders, 2014. **26**: p. 146.
3. Michie, S., et al., *Making psychological theory useful for implementing evidence based practice: a consensus approach*. BMJ Quality & Safety, 2005. **14**(1): p. 26-33.
4. Ajzen, I., *The theory of planned behavior*. Organizational Behavior and Human Decision Processes, 1991. **50**(2): p. 179-211.
5. Glasgow, R.E., T.M. Vogt, and S.M. Boles, *Evaluating the public health impact of health promotion interventions: the RE-AIM framework*. Am J Public Health, 1999. **89**(9): p. 1322-7.
6. Damschroder, L.J., et al., *Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science*. Implementation science, 2009. **4**(1): p. 50.

**Appendix 6: Triangulation Protocol for Integrated Data Analysis**

**Research questions and data sources mapped onto Normalisation Process Theory (NPT) constructs**

| NPT construct                  | Research questions explored  | Data source   |
|--------------------------------|--|---|
| <b>Coherence</b>               | How do stakeholders involved in PCTs and wider primary care context make sense of community participation on PCTs? | <p><b>Paper 1: Do primary care professionals agree about progress with implementation of Primary Care Teams: –a cross sectional study.</b></p> <ul style="list-style-type: none"> <li>• Data about the importance of community participation on PCTs as a resource</li> <li>• Data about perceptions of progress of implementation of PCTs nationally</li> </ul> <p><b>Paper 2: Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice</b></p> <ul style="list-style-type: none"> <li>• Data about multiple stakeholders sense making about community participation on PCTs</li> </ul> |
| <b>Cognitive Participation</b> | How and why do stakeholders get involved in community participation on PCTs?                                       | <p><b>Paper 2: Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice.</b></p> <ul style="list-style-type: none"> <li>• Data about motivations to do this work and champions’ reasons for supporting the work</li> </ul> <p><b>Paper 3: Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study.</b></p> <ul style="list-style-type: none"> <li>• Data about advocates/key workers who support this work in practice.</li> </ul>               |
| <b>Collective Action</b>       | What do stakeholders need to enact community participation on PCTs in daily practice?                              | <p><b>Paper 1: Do primary care professionals agree about progress with implementation of Primary Care Teams: –a cross sectional study.</b></p> <ul style="list-style-type: none"> <li>• Data about the prevalence of community representatives on PCTs nationally</li> <li>• Data from stakeholders about progress with primary care policy implementation which supports community participation on PCTs</li> </ul> <p><b>Paper 2: Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice.</b></p>  |

|                             |   |   |
|-----------------------------|---|---|
|                             |   | <ul style="list-style-type: none"> <li>• Data about enactment of community participation on PCTs in practice; roles, resources and relationships which support or impede the work</li> </ul> <p><b>Paper 3: Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study.</b></p> <ul style="list-style-type: none"> <li>• Data about enactment of community participation on PCTs in practice; views of patients/marginalised groups about priority setting for PCTs</li> </ul>   |
| <b>Reflexive Monitoring</b> | How do stakeholders evaluate the impact of community participation on PCTs? | <p><b>Paper 2: Implementing community participation via interdisciplinary teams in primary care: an Irish case study in practice.</b></p> <ul style="list-style-type: none"> <li>• Data from multiple stakeholders about the impact of community participation on PCTs</li> <li>• Data about measuring impact of community participation on PCTs</li> </ul> <p><b>Paper 3: Exploring levers and barriers to accessing primary care for marginalised groups and identifying their priorities for primary care provision: a participatory learning and action research study.</b></p> <ul style="list-style-type: none"> <li>• Data from marginalised groups about the impact of community participation on PCTs</li> </ul> |

## Appendix 7: Quality and rigour in this PhD

Techniques were built into the research to enhance quality and credibility in methods and analysis at project level and at PhD level [1]. These techniques are outlined below.

**Triangulation:** In triangulation one source of information is checked against one or more other types of sources to determine the accuracy of hypothetical understandings and to develop complexity of understanding [1, 2]. Triangulation was built into this study by collection of data across several sources in the three studies. Further triangulation was achieved by cross checking validation of research findings in PhD supervision meetings.

**Saturation:** Saturation refers to the point at which an investigator has obtained sufficient information from data collection and when further information gathered does not provide additional insights or new understandings [1, 3]. Saturation was built into projects by collection of data across several sources and holding data analysis clinics with researchers, steering group members and feedback sessions to ensure that data saturation had occurred in Papers 2 and 3. At each stage we asked “is there any data missing”, “did we expect to see something different”, “have we reached a point where we feel we will no longer generate new data”. Data saturation was also achieved via discussions in PhD supervision meetings about data saturation at data integration stage.

**Member Checking:** Member checking with participants was built into data analysis in Papers 2, and 3. Research feedback sessions were conducted with participants and offered them the opportunity to comment on findings and offer fresh perspectives. Feedback to participants was also conducted via accessible summaries across all phases of the three studies and used for write up of papers 1, 2 and 3.

**Personal biases:** Reflective notes formed part of data collection processes and were incorporated into research design and analysis across the three studies. Critical reflexivity was built into this to think through how biases, values and personal background might shape the data interpretations formed during the studies [2, 3] and influenced not only what was learned but also how it was learned [1, 2]. The PhD Candidate's memos were shared across research team members in data analysis of the three projects. These reflective processes were central to the issues of authenticity, transparency and transferability throughout write up of the PhD study also. For example, issues about positionality arose with a colleague in Paper 3 where, as GP as well as co-researcher he knew the patients in the context of his clinical work. We discussed this as a team and what effect this may have on the research. We also discussed with participants during the focus group so that we could all be clear about our boundaries in the research.

**Power relationships:** A reciprocal approach to the research encounters offered a richer engagement with research participants [2, 4]. The issues of power were

considered throughout all fieldwork sessions especially with those considered vulnerable or from marginalised backgrounds. In papers 2 and 3 (Chapters 5 and 6) this was done in the following ways; participants were supported to engage in the process by making it accessible and ensuring that participation was not dependent on literacy skills. All participants were encouraged to ask questions at the start of research sessions and throughout the research sessions as the project progressed. They were also offered opportunity to take a role in the facilitation of sessions where they wished. The PhD candidate thought about how to dismantle barriers in the research and introduced ice breakers, short breaks, food breaks and opportunity for reflection and feedback in each of the qualitative research encounters. Research team memos and notes reflected on how issues of power could be acknowledged and understood [5]. Following all research sessions, reflective notes were written up to record the research process, any difficulties arising, conflicts of interest or changes which may be required to the research processes. These reflections about power relationships within focus groups and between participants were used to guide and inform subsequent sessions. The PhD candidate was also consistently aware of attitudinal bias with members of marginalised communities and language difficulties which required consideration. Mechanisms for allowing maximum inclusion in the research sessions were developed and prepared in advance. In addition, the PhD candidate was aware of the power imbalances between herself, co-facilitators and participants. Sensitively setting out the participant and researcher roles, including clear boundaries and the necessary safe-guarding principles as described above at intervals throughout the research relationship helped to mitigate this [6].

**Audit Trail:** Best practice in research recommends that a researcher should leave a path of her thinking and coding decisions so that others can review the course of logic and decision making that followed [1, 2, 7]. Regular PhD supervision meetings were held with supervisors AMF and AH to develop thinking and to support data analysis at individual paper level and the integration of data across the three papers. Discussion about how data analysis informed the topic of community participation on PCTs was core. Analytical memos were developed and shared with AMF and AH for discussion in supervision meetings.

As described above, reflective memos and annotations developed within Nvivo and outside of this database during and following data analysis, helped to explicate thinking and support analytic decisions. This allowed the PhD candidate to share analysis and thinking with other team members and helped them to understand coding decisions. In Papers 2 and 3 double coding of 10% data was conducted by co-authors. Data analysis clinics were held between researchers and PI to discuss analysis and focus for paper write up. For data analysis and integration across the three papers for the PhD, analytic thinking and decisions were captured in minutes of PhD meetings held with supervisors AMF and AH. At the stage of data integration (described in Chapter 7), quality assurance was assured by revisiting each of the original projects and their aims and objectives. Data integration was quality assured by cross checking that the origin of data was not corrupted in any way and was true to the original data source. This system of checking and critiquing the analysis was a means of promoting consensus about emerging findings but was also a way of more deeply interrogating the data and exploring alternative explanations [8].

**Peer Debriefing:** Peer debriefing and meetings were also held with independent peer researchers when data analysis and integration was being conducted for PhD analysis. This idea of a critical friend [9, 10] is helpful in maintaining independent thinking and objectivity and supported the PhD candidate to clearly articulate the analytical processes and pathways. Based on a common action research procedure, the critical friend had knowledge and experiences in common with the PhD candidate but did not have exposure to the research setting or research data. Because of the critical friend's lack of contextual understanding, collaborative dialogue to make sense of the data increased the PhD candidate's ability to see the data within context [9]. It also provided new insights which may otherwise not have been illuminated by others close to the studies conducted.

### **References:**

1. DePoy, E., Gitlin, Laura N, *Introduction to research: Understanding and applying multiple strategies*. 2015: Elsevier Health Sciences.
2. Mays, N. and C. Pope, *Qualitative research in health care: Assessing quality in qualitative research*. BMJ: British Medical Journal, 2000. **320**(7226): p. 50.
3. Creswell, J.W., *Research design: Qualitative, quantitative, and mixed methods approaches*. 2013: Sage publications.
4. Williamson, A.E. and N. Burns, *The safety of researchers and participants in primary care qualitative research*. Br J Gen Pract, 2014. **64**(621): p. 198-200.

5. International Collaboration for Participatory Health Research, *Position Paper 2: Participatory Health Research: A Guide to Ethical Principles and Practice* 2013, International Collaboration for Participatory Health Research: Berlin.
6. Williamson, A.E. and N. Burns, *The safety of researchers and participants in primary care qualitative research*. The British Journal of General Practice, 2014. **64**(621): p. 198-200.
7. Denzin, N.K. and Y.S. Lincoln, *Strategies of qualitative inquiry*. Vol. 2. 2008: Sage.
8. Barbour, R.S., *Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?* BMJ: British Medical Journal, 2001. **322**(7294): p. 1115.
9. Foulger, T.S., *External Conversations: An unexpected discovery about the critical friend in action research inquiries*. Action Research, 2009. **8**(2): p. 135-152.
10. Deuchar, R., *Facilitator, director or critical friend?: contradiction and congruence in doctoral supervision styles*. Teaching in Higher Education, 2008. **13**(4): p. 489-500.

## Appendix 8: Survey in Paper 1

### Intro page

There have been major changes in primary care over the last decade. Some are driven by the 2001 HSE Strategy for Primary Care, for example the implementation of formal Primary Care Teams. Others are driven by the healthcare providers working together 'on the ground' formally or informally.

This survey is designed to explore your

1. perceptions of progress with the implementation of formal Primary Care Teams (PCT)
2. knowledge of, and involvement in other interdisciplinary work between professionals in primary care

**Section 1: Working with professionals from other disciplines**

**1. We know not everyone rates interdisciplinary working as important. How important is it for you to work with other primary care professionals?**

**1= not at all important and 5= extremely important**

not at all important      extremely important

**2. Do you think the HSE strategy on Primary Care A New Direction 2001 is an effective way to promote healthcare providers in primary care from different disciplines to work together?**

**1= not at all effective and 5= extremely effective**

not at all effective      extremely effective

**3. How would you perceive the general progress of implementation of formal PCTs in Ireland since 2001?**

**1= no progress at all and 5= complete implementation**

no progress at all      complete implementation

## Section 2 - Formal Primary Care Teams

Some people are members of one primary care team and some are members of more than one. Think of the PCT(s) that you are a member of and answer the questions below.

### 4. Are you a named member of a formal Primary Care Team?

- Yes  
 No  
 Not Applicable

### 5. How many formal Primary Care Teams are you a named member of?

Please type in number or not applicable

### 6. How long have you been a named member of the PCT(s)?

(Please type in a number or not applicable)

|                |                      |
|----------------|----------------------|
| PCT 1          | <input type="text"/> |
| PCT 2          | <input type="text"/> |
| PCT 3          | <input type="text"/> |
| PCT 4          | <input type="text"/> |
| PCT 5          | <input type="text"/> |
| PCT 6          | <input type="text"/> |
| Not Applicable | <input type="text"/> |

### 7. Overall, how would you describe your attendance at formal PCT meetings? (We mean any meeting that you attend as a member of the formal primary care team i.e., clinical team meetings or business team meetings as applicable to you)

- Very Frequent  
 Frequent  
 Infrequent  
 Rarely  
 Never  
 Not Applicable

**8. Overall, how do you perceive the progress of implementation of the formal PCT(s) that you are part of?**

no progress at all      complete implementation

**9. Overall, do you think that PCT members are working effectively together as a formal team?**

very effectively      not at all effectively

**10. Overall, how important are the following resources to promote team members to work together effectively as a formal team ?**

**1= not at all important and 5= very important**

|  | not at all important  |                       |                       |                       | very important        |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Protected time for meetings  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Capacity to manage workload associated with meetings                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Payment for attending meetings   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Contractual arrangements (PCT working specified in contracts with HSE) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| PCT Building to have co-located team members                           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other (please specify)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**11. Overall, how important are the following factors to promote team members to work effectively together as a formal team?**

**Please rank in order of importance 1-9 (where 1= most important and 9= least important).**

|                          |   |
|--------------------------|---|
| <input type="checkbox"/> | Resources (a combination of Q10 above)        |
| <input type="checkbox"/> | Time of meetings                              |
| <input type="checkbox"/> | GP participation                              |
| <input type="checkbox"/> | Leadership                                    |
| <input type="checkbox"/> | Clarity regarding roles in PCTs               |
| <input type="checkbox"/> | Skills knowledge and training for PCT working |
| <input type="checkbox"/> | Communication                                 |
| <input type="checkbox"/> | Community participation                       |
| <input type="checkbox"/> | Waiting list system                           |

**12. Some people have described the following benefits from formal primary care team working. Have you experienced any of the following in your PCT(s)?**

**1= Have never experienced and 3= Have frequently experienced**

|  | Have never experienced | Some experience       | Have frequently experienced |
|--|------------------------|-----------------------|-----------------------------|
| Helps me to more effectively address the needs of patients with complex problems | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Makes me feel less professionally isolated                                       | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Benefits the health of our local community                                       | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Improves patient health outcomes   | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Improves patient social outcomes   | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Improves patient psychological outcomes  | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| It makes no difference   | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Other outcomes - please specify  | <input type="radio"/>  | <input type="radio"/> | <input type="radio"/>       |
| Other (please specify)   | <input type="text"/>   |                       |                             |

**13. Overall, what aspects of formal PCT working are most satisfying for you?**

**14. Overall, what aspects of formal PCT working are most challenging for you?**

### Section 3: Other forms of Interdisciplinary Working

Some people working in primary care have told us that there are other forms of interdisciplinary working that are not always captured by the HSE documentation of formal primary care team working.

These are based on formal meetings but, also, more informal meetings and conversations between professionals in primary care during, for example, coffees and lunches.

**15. Do you agree with this statement?**

strongly agree ○ ○ ○ ○ ○ strongly disagree

**16. If you agree, is this kind of interdisciplinary work to (please tick):**

progress individual patient care e.g., to coordinate community care on hospital discharge, to refer a patient from one hospital to another?

develop new services to improve care for a whole group of patients e.g., development of a new referral system, or a new therapeutic service?

Other (please specify)

---

**17. If you have ticked any of the options in the previous question can you provide brief examples below.**

**Please include as many examples as you wish**

**18. What aspects of these formal and informal interactions across disciplines are most satisfying for you?**

**19. What aspects of these formal and informal interactions across disciplines are most challenging for you?**

## About You

### Demographics

#### 20. About your Professional Practice: Are you

- Counselor
- Community Welfare Officer
- Psychologist
- Speech and language therapist
- Occupational therapist
- Nurse Practitioner PHN
- Nurse Practitioner RGN
- Practice Nurse
- Physiotherapist
- Home Help
- HSE manager
- GP
- Practice administrator
- Practice manager
- Transformation Development Officer
- PC Manager

Other (please specify)

**21. Age**

- <35
- 35-49
- >50

**22. Gender**

- Male
- Female

**23. Years since finished professional training**

- 1 - 5
- 5 - 10
- 10 - 15
- 15+

**24. In which HSE area is your practice located**

- HSE Dublin Mid Leinster
- HSE West
- HSE South

**25. County of practice:**

**26. Type of practice:**

- Rural
- Urban
- Mixed

**27. Details of general practice (if applicable)**

- Private
- Mixed
- GMS
- Not applicable

**Section 3: About You**

**26. GMS List size if applicable:**

- ≤ 500
- 500-999
- 1000-1499
- ≥ 1500
- Not applicable

**29. Who is involved in your Primary Care Team?**

**tick all that apply**

- Clinical Psychologist
- Speech and Language Therapist
- Physiotherapist
- Occupational Therapist
- Registered General Nurse
- Public Health Nurse
- Dietician
- Pharmacist
- Administrator
- Home Help Coordinator
- Community Welfare Administration
- Counsellor
- GP
- Community Representative

Other (please specify)

### Section 3: About You

**30. Finally, is there anything else you would like to add about the issues raised in this survey?**

**31. We are interested in interviewing people about their experiences of the issues in this survey. Are you interested in becoming more involved in the next stage of this research project?**

- Yes  
 No

**32. If yes, which of the following would you be willing to discuss further?**

**You may tick more than one**

- Good experience of formal PCT working  
 Poor experience of formal PCT working  
 Good experience of other forms of interdisciplinary working between professionals in primary care  
 Poor experience of other forms of interdisciplinary working between professionals in primary care  
 Other

Other (please specify)

If yes, please email us by selecting the [Email Me](#) link in the space below and we will get in touch.

[Email Me](#)

**Appendix 9: Topic guide for the focus groups and interviews Paper 3 Chapter**

**6**

What is your experience of getting health care in your community?

Think about getting health care from ....GP, Public Health Nurse, Chiropodist, Physiotherapist etc.

How easy or difficult is it to go to see them?

What makes it easy or hard?

Tell me about the last time you visited your GP or other health care professional?

Think about other people you know: your family, your network, other e.g. friends etc.; what are their experiences?

What is the most important thing that you would like to us to tell the HSE who plan community health services?

What is most important thing or issue for the implementation group (IG) to hear?

What is the least important thing for the implementation group to hear?

Remember these are the people who may be able to do something to change the situation

*A special thank you to my two faithful Research Assistants Mollie and Lucy Eile  
(RIP) for their company on this PhD journey*

