Knowledge-sharing and collaboration in NIHR Patient & Public Involvement: a comparative case study

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Abstract

Background - The National Institute for Health Research (NIHR) place great importance on PPI in everything they fund. Anecdotally there are claims of siloed-working and duplication of activities in PPI. The Breaking Boundaries review recommended regions coordinate and collaborate to share knowledge and resources. However, little is known about opportunities for sharing and collaboration, how it might be achieved and the views of NIHR PPI staff. The aims of this project are to highlight areas for improvement and potential solutions to regional and national PPI knowledge-sharing and collaboration; and to identify opportunities to share NIHR PPI resources across the infrastructure organisations involved in research design, funding and delivery, and determine whether a streamlined model of PPI across the NIHR is feasible.

Methods - This research employed a comparative case study design. Data were collected through in-depth one-to-one telephone interviews with NIHR PPI staff from the Research Design Service (RDS), local Clinical Research Networks (locCRN), and funding panel public contributors. Supplementary data was collected to identify regional and national sharing and collaboration in the wider NIHR infrastructure from a document review and mapping exercise of NIHR PPI annual reports. Within- and cross-case analyses were conducted of the interview data using Qualitative Content Analysis. For the document review data was abstracted and the connections between NIHR infrastructure organisations mapped and presented diagrammatically. Triangulation (data and methodological) of the interview and document review data was conducted as a means of verifying the data

Within case findings - For the RDS there was little evidence of sharing resources with other RDSs. Three knowledge-sharing and collaboration themes were: a messy landscape of un-coordinated PPI; direction on effective sharing and collaboration and the longer-term goals of INVOLVE/RDS partnership; collaborative culture regionally and nationally. In the locCRN there was evidence of some neighbouring locCRNs sharing resources. Three key themes were: the value of knowledge-sharing and collaboration; PPI boundaries; and communicating nationally to facilitate knowledge-sharing and collaboration across locCRNs. For funding panel public contributors overarching key themes were, revision of public contributor training and support; cross NIHR PPI Exchange; and complementary PPI.

Cross-case findings - For RDS and locCRN , key antecedents to knowledge-sharing and collaboration were the nature of the knowledge and contribution, situational factors and individual motivation. Barriers/enablers to the act of collaboration were collaboration champions, role ambiguity, no buy-in, trust and collaboration for own gain. Synthesis of the funding panel data with that of RDS and locCRN resources highlighted opportunities to share across NIHR. Triangulation verified data from RDS, LocCRN and the document review.

Conclusions - There are three conclusions from this project. First that the NIHR culture is not one of sharing and collaboration. Second, there is duplication of NIHR PPI resources and not a great deal of sharing. Third, both the wider NIHR and public contributors could benefit from shared working. Key recommendations are: to create a community of practice for staff with a PPI role/responsibility that is driven by the needs of the stakeholders and is a community they wish to be part of; top-down changes to formalise sharing and collaboration, hold a blue skies event to re-evaluate NIHR PPI, provide regions with the skills and tools to embrace and progress collaboration and exemplars of sharing and collaborative ventures; utilise and build upon current structures to centralise PPI resources, create a register of public contributors to learn about PPI opportunities and a cross PPI exchange for public contributors as a learning opportunity and to impart their knowledge to others.

This is dedicated to my parents, Freddie and Isabel, whose resolve and certitude was always an inspiration. I know they would have been proud of me for completing this work.

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List of abbreviations

AHSN	Academic Health Sciences Network
BRC	Biomedical Research Centres
BRU	Biomedical Research Units

BTRU	Blood and Transplant Research Units
CCF	Central Commissioning Facility
COO	Chief Operations Officer
CCG	Clinical Commissioning Groups
CRN	Clinical Research Network
CRNCC	Clinical Research Network Co-ordinating Centre
CRF	Clinical Research Facilities for Experimental Medicine
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
CLRN	Comprehensive Local Research Network
DHSC	Department of Health and Social Care
DEC	Diagnostic Evidence Co-operatives
HTC	Healthcare Technology Co-operatives
HPRU	Health Protection Research Units
locCRN	local Clinical Research Network
NETSCC	NIHR Evaluation, Trials and Studies Coordinating Centre
NIHR	National Institute for Health Research
PIC	Public Involvement Community
PCLRN	Primary Care Local Research Networks
PSTRC	Patient Safety Translational Research Centres
RDS	Research Design Service

Chapter 1: Introduction

1.1 Background

Patient and public involvement (PPI) is now ubiquitous in health and social care research. PPI in research is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.[1] This involvement spans priority setting, research design and delivery(1), to the dissemination and implementation of the findings. The inclusion of 'consumers' in health research can be traced back to 1991 with the then Department of Health's R&D Strategy.[2] The UK Research Governance Framework also states 'Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research'.[3]

Over the past 20 years the literature base for PPI in research has grown substantially across the globe, though PPI is said more established in the UK in comparison to the rest of Europe.[4] The literature includes empirical studies and systematic reviews regarding different aspects of PPI in research. The literature can be categorised broadly into two interlinked areas. The first includes the 'what' (clarifying the nature and meaning), 'who' (the involvement of different types of patients/public), 'how' (ways of involving) and 'when' (which part of the research process) of PPI in research; the second the evidence base of PPI impact. In 2002 the conceptualisation - the 'what'- of PPI had not moved beyond the dimension of level of involvement[5], based primarily on Arnstein's ladder.[6] The work of Oliver[7, 8] and Gibson[9, 10] in particular, who developed frameworks focused on exploring and challenging the power differentials in the partnerships between involved patients/public and researchers, have progressed the conceptualisation of PPI to capture its dynamic nature and dimensions beyond the level of involvement. For example Gibson's framework includes the plurality of ways patients/public are involved (Monism-Pluralism), research concerns versus patient/public concerns

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[1] Delivery refers to studies that have been funded and are underway or about to begin

(Instrumental-Expressive), how much patients/public influenced decision making (Strong public-Weak Public) and whether changes suggested by patients/public were accommodated (Conservation-Change).[9] These have paved the way for further research and the development of other models and conceptual frameworks to ensure greater transparency in the process, avoid tokenistic PPI, guide research teams in effectively involving patients/public and to evaluate its impact.[7, 8, 10-19] In 2019 Greenhalgh et al published a systematic review and identified 65 different frameworks with different intended purposes.[20] With the wider adoption of PPI in research, the literature describing the experience and learning from working with different stakeholders, the ‘who’, has grown, with examples of the meaningful involvement of children[21] and young people[22], pregnant women[23], frail and seriously ill patients[24], those with rare diseases[25], dementia[26] and chronic conditions.[27] Although the frameworks mentioned above provide guidance on planning for PPI and ‘how’ to involve patients/public, there are empirical descriptive studies reporting research teams’ experiences of, and suggested best practice for, involvement [28, 29] More recently, experiences of different processes of involving patients/public, primarily co-production, have been reported.[30, 31] Similarly to the expansion of literature on the involvement of various stakeholders, so too has the reporting of PPI in different stages of the research process, the ‘when’. These include priority setting [32], the development of outcome measures[33, 34], data collection[35], qualitative data analysis[36-39] and dissemination[40], and different types of studies, for example, systematic reviews [41] and clinical trials.[42, 43]

The second body of literature has grown in response to calls to establish a PPI evidence base of the impact of PPI.[44-47] Though impact is variously defined, studies have reported the impact from the perspectives of the involved patients/public[48-52] of researchers [29, 53] and both [54-57], and on the research process or outcomes [56, 58-67] One factor contributing to the paucity of published evidence on impact is poor reporting of PPI, which has led to the development of measures to enhance the quality [68-71] Although impact is often measured using qualitative research methods that can be problematic to compare across studies, quantitative tools have also been developed and used to measure the impact on those involved [72, 73], on the research process and outcomes.[72-74] The involvement process requires scrutiny to determine whether a lack of PPI impact is attributable to substandard involvement or an 'absence of effect' (p2).[47] To address this issue tools to measure the quality of PPI in individual research projects have been developed[75-78] that can be used alongside measures of impact.

The National Institute for Health Research (NIHR), described as the research arm of the UK's Department of Health and Social Care (DHSC), is a virtual organisation that funds research units/centres and schools and individuals/teams to undertake specific research projects. The NIHR ethos is to place patients and the public at the centre of every venture and an expectation that patients/public are involved in everything they fund. To achieve this the NIHR fund PPI posts within different parts of its infrastructure and lay or public contributors for their input in specific tasks.

As the NIHR has grown since its inception in 2006, so too has PPI. In 2013/14 the then NIHR Director, Dame Sally Davies, commissioned a strategic review to assess the progress of PPI and develop a vision for the future. Data for the review were collected through an online survey, international evidence sessions, workshops, documents and supporting materials and from the literature (systematic reviews). In March 2015 a report of the strategic review 'Going the Extra Mile' was published[79] followed by an academic paper in 2018.[80] The report made 11 recommendations (summarised in Appendix A) ranging from improving communication and information about PPI to tackling the problem of ensuring diverse and inclusive PPI, with a final recommendation to assess progress three years hence in a further independent review.

Three key points from the report piqued my interest. First, the review team drew attention to a comment from the consultation 'that there is now a frenzy of public involvement activity happening across the system.' (p21).[79] Second a quotation from a Public Involvement Lead/Specialist stating 'There is far too much duplication, working in silos and re-inventing the wheel.' (p39).[79] Third, that some but not all regions were joining together to share knowledge and resources. At that time, my PhD focused on the impact of PPI in the delivery of clinical trials to time and target. However, after nine months I discovered others were already seeking to address this or a similar question. Anecdotally I was aware that those in a PPI role were questioning the number of NIHR PPI staff, had expressed concerns about silo-working and duplication of PPI activities, and felt that PPI had become an 'industry'. A national NIHR PPI lead I spoke with in connection to my original research question said:

> *The Clinical Commissioning Facility tried nationally to bring all the leads together, I think there were 400 leads in the room. So (name) totted up about how many millions of pounds that was. I think some people in NIHR see that as a success story, that there's 400. I would question that, and I would say 'Do you really need that many? What are they doing? How do you connect them?'.*

In re-thinking my research question my thoughts turned to NIHR PPI provision, and whether there *is* overlap and duplication in activities. Are all the discrete PPI activities and different patients/public involved at the various stages of the research cycle necessary? Do NIHR PPI staff share knowledge and collaborate with their counterparts regionally and nationally? Also, at the time I was a senior research methodological adviser with the Research Design Service (RDS) and our director informed us of a new directive 'One NIHR' calling for greater regional collaborative working with NIHR and partner organisations, to share resources and reduce duplication. I wondered what had driven this directive and whether it would influence PPI sharing and collaboration.

Although there is a growing body of literature about the impact of PPI in health services research design and conduct.[62] a search revealed one paper written by an RDS[81], and nothing published on NIHR PPI provision, opportunities for sharing and collaboration, how that might be achieved and PPI staff views. I returned to the Going the Extra Mile report. Recommendation 4 (Figure 1.1-1) advocates improved support for the public and researchers with PPI and 7 emphasises building partnerships and joint working regionally, within and beyond NIHR boundaries. These recommendations suggest there is a need to explore NIHR PPI provision and how to better facilitate sharing and joint working.

Figure 1.1-1 - Recommendations 4 and 7 from the Going the Extra Mile report

Recommendation 4 – Continuous improvement: INVOLVE should provide leadership and co-ordination working with workforce development initiatives across NIHR. The public and researchers need to be better supported to do PPI. PPI leads across the NIHR should have their own leadership and development programme and opportunities to network and share good practice.

Recommendation 7 – Connectivity: Grassroots level must continue to be the driving force in PPI. Further support should be given to work that is locally inspired and driven whilst strategically consistent with NIHR goals:

a. Regional PPI, engagement and participation 'citizen' forums and strategies should be developed in each of the Academic Health Science Networks (AHSN) geographies. We would expect the NIHR's Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), Research Design Services (RDSs), Local Clinical Research Networks (LCRNs), Biomedical Research Centres and Units (BRC/Us) to play a key leadership role in the development of these.

b. Regionally, locally and institutionally, NIHR infrastructure (CLAHRCs, BRU/, BRCs, LCRNs etc.) Directors and Boards should support and encourage PPI leads to identify cross-cutting activity in PPI and develop joint plans and stable resourcing where relevant.

c. Regional and local partnerships should be identified to lead on tackling key challenges in the development of PPI, beginning with diversity and inclusion.

d. Building partnerships beyond NIHR boundaries – with health and social care partners, third sector and civic organisations - should be seen as a marker of success and measured appropriately.

e. Strengthening and improving the support available to researchers locally and regionally through current delivery mechanisms such as the NIHR Research Design Service.

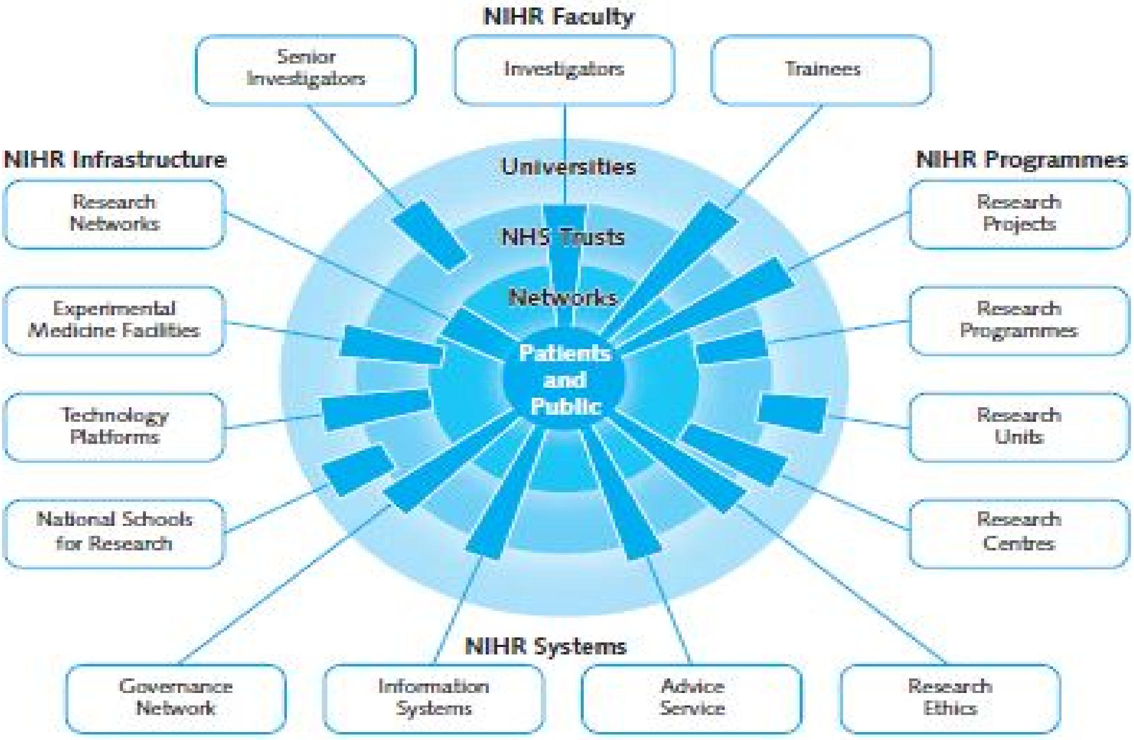
To inform my thinking and refine my research questions it was crucial to gain a greater understanding of the NIHR and what led to a situation where questions were being asked about the number of staff with a PPI remit and there were concerns about duplication of activities. This understanding was achieved in part through a review of NIHR websites, annual progress reports and briefing documents. To address gaps in the documentary sources, namely CRN PPI prior to its restructure in 2014 and the rationale for the One NIHR campaign, I conducted informal 'interviews' with individuals who had this knowledge (previous locCRN PPI staff, NIHR National PPI staff and a CRN Clinical Director from a region where they had launched a One NIHR initiative). There was no formal analysis of the interview data as this was for information gathering purposes only. Illustrative quotes have been used with the permission of the individuals.

In the next section I present a review of the inception and growth of the NIHR and all of its facets. This includes how it is structured and managed, its specification for, and expectations of, PPI in its infrastructure organisations from the beginning. The remainder of the chapter outlines the refined research questions, aims and objectives, proposed research approach and delimitations. It concludes with an outline of the thesis structure.

1.2 The National Institute for Health Research - inception and growth

In response to concerns about the decline of clinical research in the UK[82-85] the then Director of the Department of Health Research & Development, Professor Dame Sally Davies, conducted a national consultation of key stakeholders in 2005 to find solutions to the challenges identified and outline a strategy.[86] One objective from the strategy is the creation of a 'National Institute for Health Research' in England to 'provide the framework through which we can position, manage and maintain the research, research staff and infrastructure of the NHS in England as a virtual national research facility' (p9). Figure 1.2-1 illustrates the proposed scope and remit of NIHR.

Figure 1.2-1 – NIHR in England



From: Best Research for Best Health. A new national health research strategy 2006

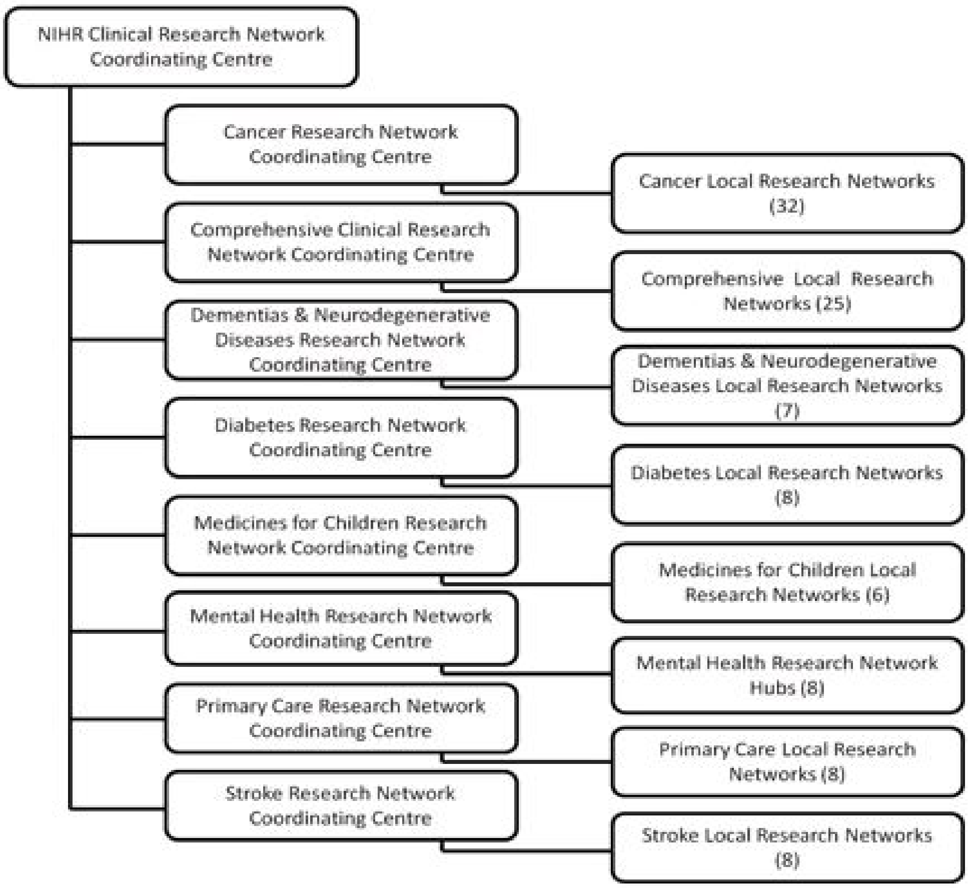
In 2006 Sally Davies and her team set out to build the NIHR infrastructure, establish sources of research funding and develop systems to facilitate research. Over the following 10 years the NIHR introduced initiatives and services, established several infrastructure organisations and a range of research funding streams that span the innovation pathway. One contact describes the NIHR ethos in early in its development:

> *‘When Sally and Russell and others set up NIHR of course they did it in a very iterative way. … but … their philosophy was “Let many flowers bloom” it really was, and with the high expectation some would fail, but it was about generating a really creative landscape where there hadn’t been anything before.’ Contact 04 - PPI National*

Clinical Research Network

In the first year the Cancer Research Network (established in 2001) was brought under the auspices of NIHR and to build on its success in increasing trial recruitment rates[87], the Clinical Research Network (CRN) was created to support the timely delivery of commercial and non-commercial research in the NHS. This comprised of six topic networks, a Primary Care Network (PCN) and Comprehensive Local Research Network (CLRN) with separate geographical presences (satellites) culminating in 102 networks (Figure 1.2-2).

Figure 1.2-2 – Clinical research networks and co-ordinating centres in 2012



From Kotting et al 2012.[88]

What was the PPI provision in the CRN? Did each of the 102 networks have PPI? As it was difficult to determine this from the available websites, this information was collected from three NIHR PPI leads. An example topic network, said to be typical of most others, had eight geographical locations, each with a public group of 10-15 members. Researchers could meet with the group, present their research ideas and obtain feedback. They would comment on study documentation, advise researchers struggling with recruitment and sometimes work more closely with a research team to develop a study, This PPI Lead also commented on the collaborative aspect of these satellite networks:

> *'It was popular and it was growing. A number of the groups had waiting lists for researchers to come to them […] and they were working with other (NIHR) partners, so the group that we set up in (name) was working closely with the CLAHRC[2] and did similar things with some of the Biomedical Research Centres when they first set up as well. So it was starting to knit together quite nicely.' Contact 01 – PPI Lead in a topic network*

The 25 CLRNs encompassed research into the disease areas not covered by the six topic networks and PPI differed from that in the topic networks. Although created a year later than most of the topic networks, PPI was said to have been slow to develop in the CLRNs. According to the contact, apart from public involvement at a governance level, PPI in individual projects came much later around 2011/12 and had a narrower focus.

> *'There was a separate expectation of the CLRN in that it should be entirely focused on delivery. […] And so the PPI aspect was also a bit different as well. […] and the Department made it very clear that that's what they wanted the Comprehensive to do, and not to do development work.' Contact 02 – CLRN PPI*

The focus on PPI in research delivery was a challenge as 'nobody had expertise in that area at that time' (Contact 02). One solution was to encourage NHS Trusts in the different localities to involve patients and the public in research development.

For PPI in the PCLRN the picture was different to both the CLRN and topic networks. Unlike the CLRN, the eight regional PCLRNs had PPI staff, though they were often in a dual role. They varied in their scope for PPI despite the focus from the national

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[2] Collaborations for Leadership in Health Research Care

perspective being on study delivery. Some of the satellites set up local PPI networks which were said to be ‘very successful’. Echoing the previous contact, PPI in delivery was said to be a challenge

> *‘There was a lot of variation across the regions based on history, really. …If they were based in the universities I think they tended to get more involved in the design. (Um) Erm but … we didn’t have the resources to cover activities relating to anything that wasn’t delivery. And we spent quite a lot of time … trying to define where delivery starts and ends.’ Contact 03 – PCLRN PPI*

PPI in the delivery of studies was achieved in some of the satellite networks where it was embedded in a trouble-shooting role for studies that were struggling to recruit.

The national perspective was to try to *influence* the CLRN and PCLRN regions to limit their activities to study delivery only. This was a challenge to enforce for those responsible for PPI across the satellites and regional hubs.

All change

The creation of the CRN produced tangible evidence of improvement in research delivery, with a greater number of studies opened and more patients recruited. For example the number of studies opened by the Stroke Research Network more than trebled in two years from 57 (2006-7) to 189 (2009-10).[89] Despite its success the CRN was a very costly structure. The seven topic networks each had separate geographical presences, for example the Mental Health Research Network had eight offices. The 102 research networks were supported by nine co-ordinating centres (Figure 1.2-2). In 2014 with the end of the five-year contract, a decision was made to streamline the organisation and move to 15 local CRNs and one national coordinating centre. The reasons were to ensure the structures were ‘fit for purpose, made best use of tax-payers’ money and were in tune with the NHS which has undergone two major restructures since the Network formed’.[90]

Research units, centres and schools

To build an infrastructure with the facilities and people for a thriving research environment seven types of research units/centres/schools (NIHRio) were created between 2006 and 2008 (resulting in 62) primarily across England. These were funded through open competition, typically for a five-year period, in partnership with a university and one or more NHS organisations, or with charities, research councils and Public Health England. In the subsequent period up to 2017, 12 new types of NIHRio were created. Figure 1.2-3 demonstrates the remarkable growth in the number of NIHRio created and funded in the NIHR's first 10 years.

Figure 1.2-3 - The growth in the number of research schools funded from 2006-2017

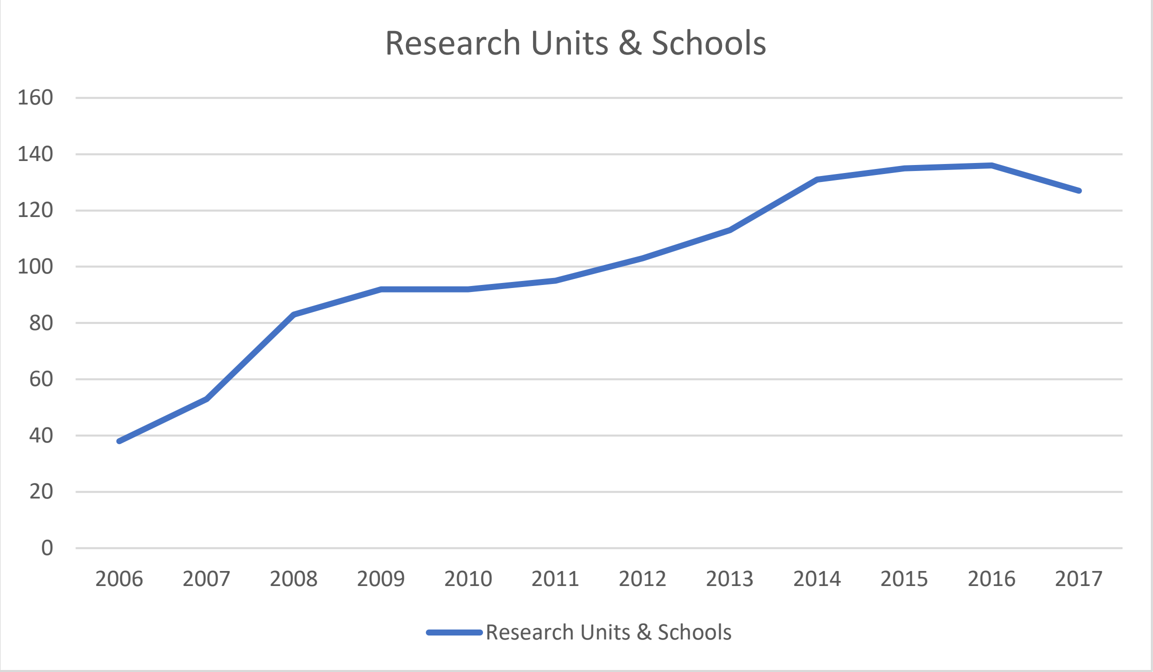

Figure 1.2-4 provides a description of the NIHRio created up until 2017. The earliest NIHRio had an experimental focus and spanned the invention and evaluation spectrum. Little is documented about the rationale for this initial focus though insufficient translational research had been identified as a gap in the UK and 'Basic research was poorly translated, missing important benefits for patients' (p6).[91]

Figure 1.2-4 – Description of NIHR infrastructure organisations from 2006 - 2017

Year created	NIHR infrastructure organisation	Number funded
2006	**Clinical Research Facilities for Experimental Medicine** – provide purpose-built environments for patient-centred research. Clinical researchers make use of cutting-edge clinical facilities, technologies, expertise and have access to patients. Collaborations between basic and clinical scientists are facilitated so that advances in research can lead to improvements in healthcare	**19**
	Experimental Cancer Medicine Centres – in partnership with Cancer Research UK, focus on speeding up the process of cancer drug development and the search for cancer biomarkers to diagnose cancer, predict the aggressiveness of the disease, or show whether a drug will be effective in a specific patient and at what dose.	**14**
	School for Primary Care Research - comprises the leading academic centres for primary care research in England. Their role is to conduct high quality research and train future research leaders with an aim to improve everyday practice in primary care.	**5**
2007	**Biomedical Research Centres**–conduct and support translational research to transform scientific breakthroughs into life-saving treatments for patients.	**11**
	Healthcare Technology Co-operatives –to develop concepts, demonstrate proof of principle and devise research protocols for new medical devices, healthcare technologies or technology dependent interventions to improve patients' quality of life and the effectiveness of healthcare services.	**2**
	Patient Safety & Service Quality Research Centres (PSSRC) - brings together NHS professionals with academic experts from a wide range of backgrounds, including management and the social sciences, to focus on investigating ways to improve the care of patients.	**2**
	NIHR BioResource – brings together volunteers, patients and their relatives (associated with six NIHR BRCs and one NIHR BRU) who have consented to be approached about experimental medicine studies on the basis of phenotypic and genotypic data.	**1**
2008	**Biomedical Research Units** –conduct and support translational research to transform scientific breakthroughs into life-saving treatments for patients.	**20**
	Collaborations for Leadership in Applied Health Research and Care – bring together universities and NHS organisations including primary care, to conduct applied health research that is transferable across the NHS to provide the highest quality patient care and outcomes.	**9**
	Patient Research Cohort Initiative - A joint initiative, funded by the MRC, the NIHR in England, the Wales Office of Research and Development and the Chief Scientist Office of the Scottish Government Health Directorates. to create small, extensively defined groups of patients to help detect, treat or prevent disease	**11**
2009	**School for Social Care Research** – aims to increase the evidence-base for adult social care practice. The school conducts primary research in the adult social care sector in England.	**6**
2011	**Centre for Surgical Reconstruction and Microbiology** – brings military and civilian trauma surgeons and scientists together to share advanced clinical practice in the battlefield and innovation in medical research to benefit all trauma patients in the NHS at an early stage of injury	**1**
	Translational Research Partnerships – bring together world-class investigators in leading academic and NHS centres to support collaboration with the life sciences industry in early and exploratory development of new drugs and other interventions. The NIHR Biomedical Research Centres and Units form the bedrock of these partnerships.	**2**

Year created	NIHR infrastructure organisation	Numbers funded
2012	**Patient Safety Translational Research Centres** – conduct and support research to investigate ways to improve the safety, quality and effectiveness of the services that the NHS provides to its patients. FORMERLY PSSQRC	**2**
	School for Public Health Research - conducts research into public health with an emphasis on what works practically, can be applied across the country and better meets the needs of policy makers, practitioners and the public.	**8**
2013	**Diagnostic Evidence Co-operatives** – new infrastructure to act as centres of expertise to catalyse the generation of evidence on in vitro diagnostic medical devices (IVDs) that is required by the NHS and by industry, and which demonstrates the benefit to patients and the healthcare service.	**4**
	The MRC/NIHR National Phenome Centre - enables scientists to better understand and tackle diseases that are triggered by environment and genetic causes, and to develop strategies for their prevention and treatment. It uses nuclear magnetic resonance and mass spectrometry technology to give the most accurate readings to date of the exact chemical make-up of people's blood and urine.	**1**
2014	**Translational Research Collaborations in Dementia and Rare Diseases** – Bring together world-class health researchers within designated Biomedical Research Centres and Units to effectively pull discoveries from the country's world-leading basic and translational research into real benefits for patients, share their considerable resources and world-leading expertise to improve treatment and care, and to maximise the impact of NIHR investment. The Collaborations also play an important role in collaborating with the life sciences industry. (**FORMERLY Translational Research Partnerships)**	**2**
	Health Protection Research Units – supports Public Health England (PHE) in delivering its objectives and functions for the protection of the public's health in priority areas.	**13**
2015	**NIHR Biosample Centre** – robotic biosample repository, enhancing the nation's capacity to support research into disease mechanisms, diagnosis and treatment.	**1**
	Blood and Transplant Research Units – support the needs of NHS Blood & Transplant through an environment to focus on priority areas, provide high quality research evidence and translate advances in research into benefits for users of NHSBT services**.**	**4**
2017	**Policy Research Units** - undertake research to inform government and arms-length bodies making policy decisions about health and social care.	**2**

Compiled from the NIHR website (https://www.nihr.ac.uk/research-and-impact/research/research-units-and-schools.htm) and 1.1 The National Institute for Health Research Version 12 (July 2016)

Toward the end of their funding period most NIHRio could apply for a second round. In subsequent rounds for each type of research unit NIHR sometimes increased the number of organisations they funded. However, adapting to the changing research environment and the performance of the NIHRio, some were discontinued or merged. A table documenting the establishment, dissolution and renewal of NIHRio chronologically is provided in Appendix B.

Tender documents(3) (2011 to 2016) were obtained to try to understand the expectations for PPI in the formation of these NIHRio. They revealed variation in the specifications for PPI across the NIHRio and over time (Table 1.2-1). Requests for PPI costs were absent in six of the 13 tender documents. This occurred in some of the earliest tender documents (2011 – 2013) though INVOLVE had published guidance on payment for involvement in 2007[92] and 2009.[93] Where costs were requested there was some guidance on what these may cover.

Table 1.2-1 –PPI specifications in the NIHR tender documents

NIHRio & Year of tender	Provide Strategy for PPI	Finalise strategy in first year of funding	Expectations for PPI rather than strategy/plan	Track record of PPI in institution	Provide Costs
Clinical Research Facilities (2011)	●				
School for Primary Care Research (2014)	●				●
Biomedical Research Unit (2011)	●				
Biomedical Research Centre (2016)	●	●			●
Patient Safety & Service Quality Research Centres (2016)	●	●			●
Health Technology Co-operative (2012)			●		
Collaboration for Leadership in Applied Health Research and Care (2013)	●				
School for Social Care Research (2013)				●	●
School for Public Health Research (2015)				●	●
Diagnostic Evidence Co-operative (2012			●		

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(3) These are the documents the NIHR release to institutions to bid for funding to create an infrastructure organisation

Health Protection Research Units (2012)			●		
Blood and Transplant Research Unit (2014)	‘Details’				●
Patient Safety Translational Research Centres (2016)	●	●			●

One limitation of these documents as an information source was the inability to obtain the full guidance for all NIHRio to compare PPI specifications (see Appendix C for the documents obtained). However, of those obtained there was variation within document type across the NIHRio. For example, the 2011 ‘Invitation to submit pre-qualifying questionnaire’ for the Biomedical Research Unit requested a PPI strategy yet for the Patient Safety Translational Research Centres the same year there was no reference to PPI. In the 2011 ‘Invitation to submit application’ tender documents for the School of Public Health Research the PPI details were sparse compared with the 2015 document where a greater level of detail about the institution’s track record in PPI was requested, including processes for monitoring and evaluating the impact of activities.

As the tender documents were issued by the Central Co-ordinating Commissioning Facility (CCF) who support the NIHRio one might expect standardisation of PPI requirements. Considering the differences across the tender documents over time, it is not clear whether this is an indication of a greater understanding of the scope and potential for PPI within each NIHRio on the part of NIHR, an increased focus on involving patients/public, or a realisation that the NIHRio needed more guidance.

Developing research ideas, commissioning and funding research

Research Design Service

Situated within NIHR systems, ten Research Design Services (RDSs) were established and funded across England in 2008 for a five-year period. Their remit was to increase the number and quality of applied health and social care research funding applications submitted to NIHR. Their geographical location maps on to the previous 10 Strategic Health Authority areas - East of England, East Midlands, London, North East, North West, South Central, South East Coast, South West, West Midlands and Yorkshire and Humber. Those who consult the RDS – academics, NHS staff and small and medium enterprises - receive free advice and support to develop their research ideas into strong, scientifically robust funding applications and to build a team of investigators. The RDS supports applications to all of the NIHR funding programmes, to other national peer reviewed funding programmes, for example research councils, and the larger charities. Through the RDS, clients can obtain specialist methodological advice and guidance on PPI in developing a funding application and for the duration of their study should it be funded. Although the original tender was not available, a document from 2012 (the second round of funding) was obtained. It describes the objectives of the scheme and states:

> *'Each RDS must, at its core, have access to health economic and statistical expertise, systematic review and research methodological expertise'.*

The document refers to the input of patients and public, and states that the RDS should offer advice and guidance on contacting collaborators including 'patients, patient representatives and the public'. The PPI was more directive in terms of staffing compared to the NIHRio tenders though a strategic plan was not asked for at that time. The document specifies that the RDS will:

> *'Facilitate user involvement in research design. This is likely to require (although is not restricted to) an identified lead for patient and public involvement (PPI) in the senior RDS team as well as special PPI advisor(s), resources for supporting involvement in the design stage, and where appropriate, become actively involved in local PPI networks*

> *and groups (but not to duplicate the activities of INVOLVE in promoting greater public involvement in health and social care research).'*

Although there is no RDS National PPI Strategy, once funded they must outline progress against their plan in annual reports to national NIHR as the majority of the NIHRio do. In 2015 a new joint contract between INVOLVE and the RDS was announced (See PPI in the wider NIHR section).

Funding programmes

Concurrent to the building of the infrastructure, NIHR introduced a range of research funding programmes and personal awards. The two research programmes already in existence within NHS Research & Development (Health Technology Assessment and the Service and Delivery Organisation) were brought under the NIHR umbrella in its first year of operation. Over the next 10 years further new sources of funding were established (Table 1.2-2).

Table 1.2-2 – NIHR research funding streams created between 2006 and 2015

Year established	Funding
2006-7	Programme Grants for Applied Research Research for Innovation, Speculation and Creativity Research for Patient Benefit
2007-8	Efficacy and Mechanism Evaluation Methodology Research
2008-9	Healthcare fellowship scheme Public Health Research Invention for Innovation (i4i) Health Services Research
2011-12	Research Professorships Knowledge mobilisation fellowships i4i Challenge award
2012-13	Health Services and Delivery Research*

2015	Integrated Clinical Academic Programme

*The existing Service Delivery Organisation and Health Services Research funding streams were merged into Health Services and Delivery Research in 2012.

Those applying for research funding are expected to involve patients and the public in the design, conduct and dissemination of research, or provide a strong justification for not doing so. The funding application forms and guidance for applicants for two funding streams, Research for Patient Benefit (RfPB) and the Health Technology Assessment Programme (HTA) (commissioned call) were obtained for 2012 (the earliest obtainable). The structure of the RfPB application form prompts the applicant to report: whether patients/public were involved in identifying the research question and preparing the application, and if so how; the plan for PPI in the proposed research including training and support for those involved; the benefits of PPI; if patients/public were not, or will not be, involved to explain why. The HTA funding application form did not include any questions about PPI. However, in the commissioning brief applicants were encouraged to involve patients/public and to describe the plan – aims and methods - and budget for PPI within the application. The guidance for PPI concluded with:

> *‘Applications that involve members of the public will not, for that reason alone, be favoured over proposals that do not but it is hoped that the involvement of members of the public will improve the quality of the application.’*

This difference could be attributable to these funding streams being managed by different co-ordinating centres.

To ensure the patient voice is present in informing the research agenda and in what is funded, NIHR funding applications undergo internal and external lay review.[94] Although it is not clear whether lay representatives were involved in the funding award infrastructure from the beginning, NIHR reported an increase of lay members on prioritisation and funding boards and lay reviewers from 425 in 2012-2013[95] to over 1000 in 2013-2014.[96] In 2012 the involvement of public members at the NIHR

Senior Research and Career Development Fellowship interviews was piloted. This was deemed successful - although there are no details of how this was measured - and expanded to all of the fellowship panels from 2014.[95]

PPI in the wider NIHR

As illustrated earlier (Figure 1.2-1) the NIHR's ethos has been to place patients at the centre of the endeavour. In the first available NIHR Annual Report[97] for 2009/10 they state that their

> *'efforts to include patients and the public in research is in keeping with the NHS Constitution, which states that research is a core part of the NHS and enables the health service to improve the current and future health of the people it serves.' (p12).*[97]

Two other NIHR PPI-specific aspects of note are the work of INVOLVE and the appointment of a National Director for Public Participation and Engagement.

INVOLVE, whose remit is to 'support active public involvement in NHS, public health and social care research'[98] was brought under the auspices of NIHR in 2006.The role of INVOLVE is described as one to 'create an environment where public perspectives are integrated in all aspects of research to enhance its quality, relevance and acceptability'.[99] Over the years the work of INVOLVE has featured in their own newsletters and NIHR Annual Reports. This work can be categorised as resources and information to: improve the quality of PPI; educate researchers/organisations and the public about PPI; provide an evidence base for the impact of PPI; support researchers in involving patients/the public; and equity, in financial terms, for involved patients/public (see Appendix D for tables of documents). Within these categories INVOLVE also led on various initiatives as described in Table 1.2-3.

Table 1.2-3 - INVOLVE PPI initiatives

Areas	**Initiatives**	
Improve the quality of PPI	Worked with the Health Research Authority on their PPI strategy (2012).[95]	International Patient and Public Involvement Network –to develop standards and policies, share information on PPI and measure its impact in research (2016).[100]
Educate researchers, organisations and the public about PPI	PPI training to Research Ethics Committees (2012)	
Provide an evidence base for the impact of PPI	Perspectives of Lay members of National Research Ethics committees (2009) [101]	PPI in applications for ethical approval 2010[102] and 2012[103]
Support researchers in involving patients/the public	People in Research searchable database (2007)	

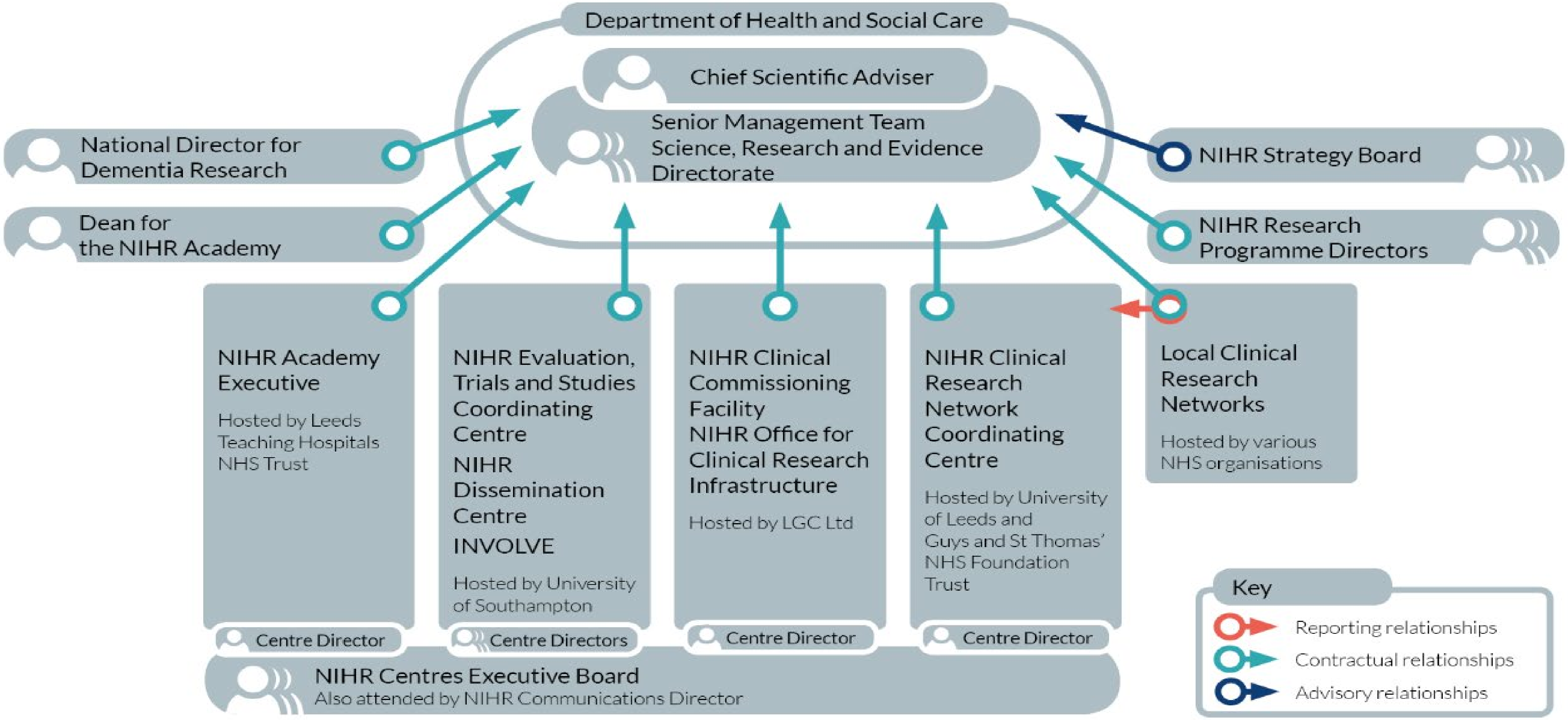
In 2015 a new joint contract between INVOLVE and the RDS was announced. To quote from the INVOLVE website 'The INVOLVE-RDS Partnership will explore and support existing networks and forums in each of the 10 RDS regions, and create new networks where none exist'.[104] The goal of this partnership is to respond to the findings of the Going the Extra Mile review[79] to 'ensure that the role of public involvement activities in different parts of the overall system is clear, well-understood and properly co-ordinated' (p22). The focus is on a new model 'utilising existing NIHR RDS national, regional and local partnerships'.[105]

Simon Denegri, who was the Chair of INVOLVE at the time, was appointed to the post of NIHR National Director for Public Participation and Engagement in 2011. The aim of this appointment was to drive initiatives to improve rates of research participation and work closely with stakeholders to build successful partnerships and collaborations.[95] In 2013/14 he led the strategic review of public involvement in research, 'Breaking Boundaries' that culminated in the 'Going the Extra Mile' report mentioned earlier.[79]

How NIHR is managed

As with most public sector organisations, NIHR has a hierarchical management structure (Figure 1.2-5). Seven co-ordinating centres, hosted by several NHS Trusts,

Figure 1.2-5 - NIHR Management Structure



From: https://www.nihr.ac.uk/about-us/our-governance/

universities and life science organisations, manage the day-to-day work of NIHR. The CCF manages five research-funding programmes, 11 infrastructure organisations and research schools/units, and the RDS, the NIHR Evaluation, Trials and Studies Co-ordinating Centre (NETSCC) manages five research-funding programmes, the NIHR Journals Library and the James Lind Alliance Priority Setting Partnerships, and the NIHR Clinical Research Network Co-ordinating Centre (CRNCC) manages the CRN.

One of the contacts raised an issue with the management structure, in particular the co-ordinating centres.

> *'Now a lot of our administrative, if you can call it that, hubs, are coordinating centres - five coordinating centres – so like the Commissioning Facility or NETSCC or INVOLVE, and each of those is contracted very separately through the Department of Health, and that contract culture actually is um runs counter to collaboration because what happens is the centres operate towards what their contract tells them to do, not generally for the great good. And I think that's a sort of fundamental issue that's never really been addressed.' Contact 04 – PPI National*

Reporting structures

With this huge investment in health and social care research, NIHR must ensure each part of the infrastructure is delivering upon their agreed objectives. However, the planning and reporting varies between NIHRio. To monitor performance, most NIHRio, and the RDS, submit a structured annual report to their respective co-ordinating centres. The PPI content of the NIHRio reports are compiled into one document that is shared within each NIHRio for comment and then made available on the NIHR website to 'support and promote the sharing of knowledge, learning and good practice across the NIHR and beyond.'[106] Each Programme Team in the co-ordinating centres review both progress against the original/previous PPI plan or strategy and the proposed future direction, and may request further information and/or suggest minor changes to implement in the subsequent one-year period. In contrast the CRN appears to have a more complex system of reporting and monitoring. It has an annual cycle in which the CRNCC releases an updated Performance and Operating Framework (POF) with contractual obligations and accompanying Contract Support Documents for each of the local CRNs (locCRNs) to fulfil. These include performance indicators for research delivery and more general ‘deliverables’ from within their cross-cutting themes such as communications, PPIE and workforce development. For example, the POF may state that locCRNs need to collect a number of case studies from research participants to highlight research impact. locCRNs will outline how they intend to deliver in their annual plan and the following year progress/completion of the plan is monitored.

The meaning and origins of One NIHR

Internal communications to the CRN, NIHRio and RDS tend to be via their respective co-ordinating centres. However, NIHR ran a campaign in June 2015 called ‘One NIHR’ directed at all NIHR personnel.[107] One NIHR was intended to encourage those working for, or funded by, the NIHR to present a unified front and identity to others. In a video clip, Sally Davies states that the NIHR ‘looks complex’ to outsiders[108] and encourages NIHR staff to use the One NIHR website with its facts and figures to ‘become ambassadors’ for NIHR.

It is important to devote some time to consider this campaign as there were different interpretations of its meaning and intention. Promoted in the north east region as a move to reduce duplication of activities, and to increase collaboration and sharing across NIHR, it led to different parts of the local NIHR infrastructure meeting to discuss how they could maximise opportunities to collaborate, improve efficiency and develop a One NIHR web presence. As the focus of the campaign from the website and the local interpretation differed so widely, I tried to discover the origins of the so-called One NIHR directive for more greater collaboration and sharing. One contact (Contact 04) said it came from conversations in the NIHR Strategy Board over a period of time in relation to two issues: first that NIHR could be more cohesive and co-ordinated; and second, as the public found it difficult to navigate and understand, its presentation to the outside world could be improved.

> *'One NIHR is one of those interesting instances where it's very difficult to pinpoint a specific moment in time or place where a decision was taken to pursue a campaign or a message around One NIHR and that probably reflects a much wider issue about how NIHR works but how government organisations generally work these days, especially if they're distributed entities like NIHR.' Contact 04 – PPI National*

1.3 Refinement of the research question(s)

Section 1.2 illustrates the complexity and evolution of NIHR as a nationally distributed multi-faceted organisation where PPI is – or is expected to be - embedded in all its facets. The original aim to build a creative research landscape where there was none before was achieved in a relatively short time. However, this has resulted in a complicated structure. Echoing the comments of others who contributed to this picture, one of the contacts summarised the NIHR structure at the time of conducting this project:

> *'The consequence is that ten, twelve years on you have a very messy landscape and you need to somehow farm it better. And I think we're at that point where we recognise we need to farm it and take care of the land better than we had to in the past.' Contact 04 – PPI National*

Also highlighted is a lack of co-ordination for PPI in the tender documents. None of the later tender documents referred to the possibility of cross NIHRio PPI collaboration or sharing which is surprising considering the recommendations from the Going the Extra Mile review for staff to network and share.[79] This portrays a picture of different parts of NIHR operating independently without awareness of other parts, connection and oversight. The potential consequences of a lack of collaboration are for PPI to evolve in isolation from other NIHR partners and for silo-working which could perpetuate a culture of not sharing or collaborating. The impact of such a culture is missed opportunities for developing both efficiency and best practice.

NIHR expect PPI in their infrastructure, yet there is little research into what is provided, what is duplicated and what could be shared. With a reduction in duplication and greater collaboration of PPI staff could there be a model of PPI that is more streamlined? If so, what would be the barriers and enablers to such a model? PPI expertise and resources are two aspects that could easily be shared across the NIHR. Greater collaboration and pooling of resources could address problems of duplication and enable staff to undertake more creative and innovative PPI. Considering the issues identified in the Going the Extra Mile report, and the paucity of research into NIHR PPI in the research pathway, I revised my research questions to the following:

- What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHR?
- What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?
- Is a seamless model of NIHR PPI feasible?
- What would this model of PPI look like?

As demonstrated earlier, NIHR has a large number of infrastructure organisations. It would not be possible to include all in a research project. I selected the RDS and locCRN as the main focus as their remit is research design and delivery respectively. They also focus on applied research where arguably PPI is more straightforward than, for example, in a laboratory-based study. I thought it important to explore PPI at the funding stage and include public contributors who are members of the NIHR funding panels for applied research. These three groups were potentially where duplication in PPI could occur.

1.4 Research aims and objectives

There is a need to rationalise PPI and explore the potential for a more collaborative model and the optimum conditions required for this model to work. Therefore, the aims of this project are to determine whether a streamlined model of PPI is feasible and to highlight areas for improvement in, and potential solutions to, regional and national knowledge-sharing and collaboration. The objectives are:

- to document NIHR PPI provision at the research design, funding and delivery stage and identify any duplication and opportunities to share
- explore the barriers and enablers to regional and national PPI knowledge-sharing and collaboration

The fragmented structure and other factors such as how NIHR communicates, its PPI reporting and management structures, and the INVOLVE/RDS partnership will be important to consider in the interpretation of the findings of this project and their influence on sharing and collaboration.

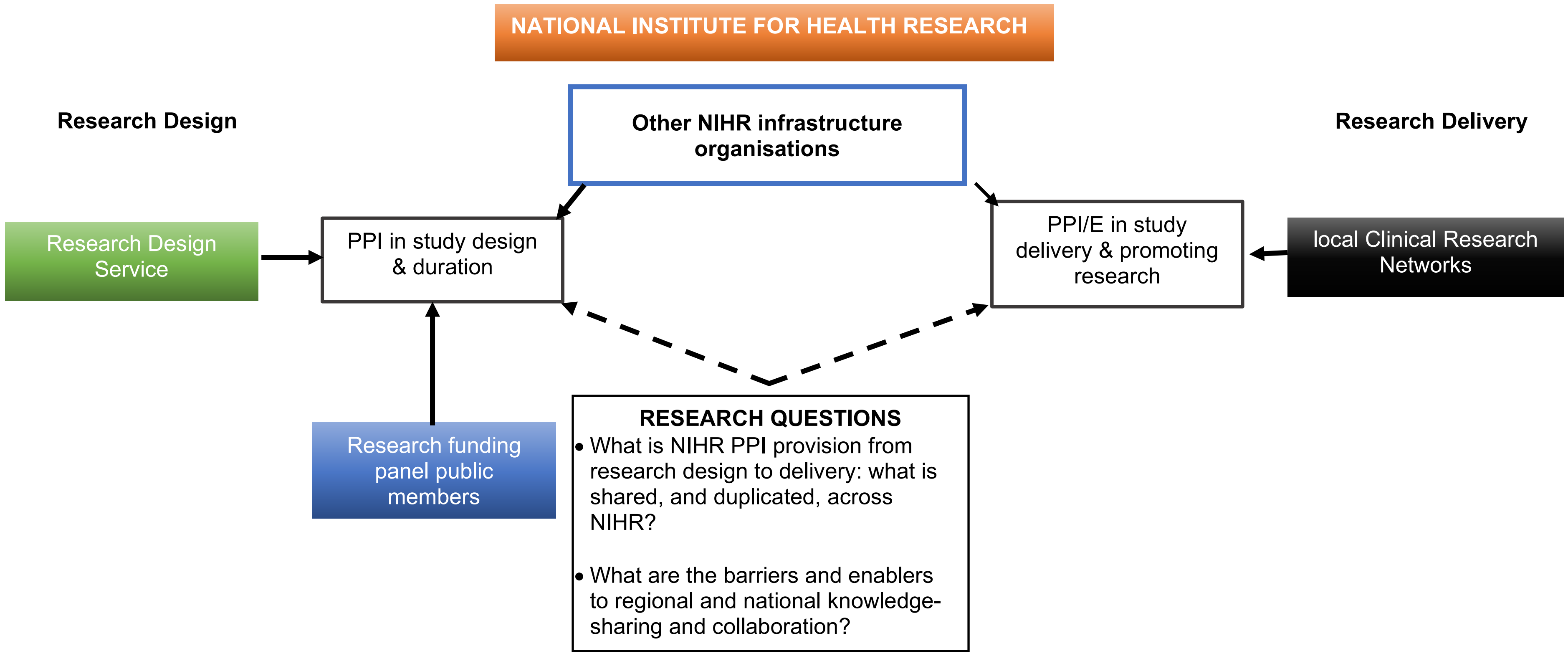
In the next section the rationale for the chosen methods is given.

1.5 Research approach and methods

As the focus was sharing and collaboration across regions and nationally, I selected a comparative case study design. This provides a cross-case analysis of the barriers/enabler to sharing and collaboration and a picture of PPI provision and resources. The three cases of interest in Figure 1.5-1 represent design (Research Design Service - RDS), funding (funding panels public members), to delivery (local Clinical Research Networks - locCRN). To supplement the RDS and locCRN data, a document review of NIHRio’s PPI Annual Reports will be conducted. This will provide information on PPI resources, collaboration and sharing across NIHR regionally and nationally.

With an interest in PPI staffs’ perceptions of sharing and collaborative working and the experience and contribution of public members of funding panels, a constructivist paradigm was the most appropriate approach to guide my research and address the

Figure 1.5-1 - The place of the RDS, funding panel public members, CRN and other NIHR infrastructure in the research cycle



specific research questions. Within this paradigm, knowledge and reality are subjective and constructed within individuals. Due to the exploratory nature of the study, qualitative methods were most appropriate. Qualitative in-depth interviews were chosen to reflect the nature of the research questions.

The findings from all data sources will be synthesised to determine: what could be shared; the perceived barriers and enablers to knowledge-sharing and collaboration; and whether a streamlined model of PPI is a feasible.

1.6 Delimitations

It is beyond the scope of this project to explore, in detail, PPI provision in all NIHRio and beyond. A more manageable option is to focus on two of the major contributors to the design and delivery of research in NIHR, the RDS and CRN respectively, and to PPI in research funding programmes. To supplement this data a document review of PPI annual reports available for 16 NIHRio will be conducted.

There is no plan to collect data from patients/public involved in NIHR, apart from the public members of the funding panels. Again, this is beyond the scope of this project particularly as the focus is primarily on the perspectives of NIHR staff. A future project could seek the views of the non-salaried NIHR lay representatives and public contributors on the proposed streamlined model.

1.7 Thesis structure

Figure 1.7-1 provides an overview of the thesis structure. A brief outline of each chapter is provided in this section. The first chapter comprises an introduction to the research questions, description of NIHR, research aims, objectives and approach.

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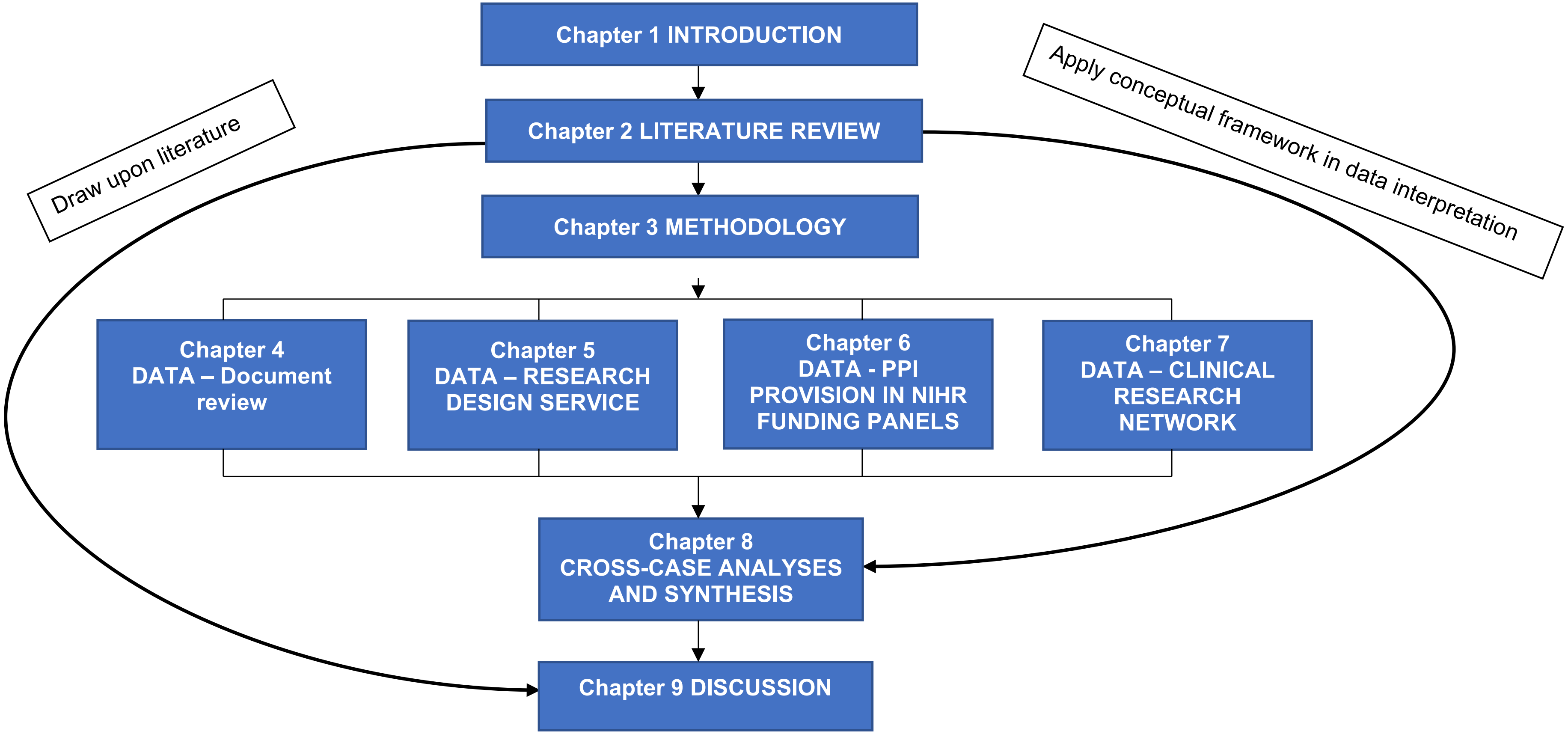
Figure 1.7-1 - Structure of thesis



Chapter 2 – Literature review

Here the pertinent literature regarding the barriers and enablers to workplace knowledge-sharing and collaboration is reviewed. There is a large body of literature on knowledge-sharing and collaboration in the private sector and across organisations. As there may be differences in organisational structure, culture and in the attitudes of the workforce in the private/public sectors, the review is restricted to studies conducted in public organisations. Additionally, although NIHR has many components it is a single organisation, the focus is on studies exploring barriers and enablers to *intra*-rather than *inter*-organisational knowledge-sharing and collaboration. The review informs the development of a conceptual framework to guide interpretation of the data.

Chapter 3: Methodology

This chapter provides an overview of both the chosen and potential alternative approaches (paradigm), ontological and epistemological stances, conceptual frameworks, research designs, methods of data collection and analyses. Following this a detailed and critical account of the research procedures, for example, sample selection, identification and recruitment of participants, and data collection is given. The subsequent sections discuss the role of the researcher and study limitations.

Chapter 4 – A regional picture of NIHR PPI sharing and collaboration – document review and mapping

As it is not possible to collect in-depth data on PPI provision, sharing and collaboration from all NIHRio this is collected through a document review. The information source is the annual NIHR infrastructure PPI Reports from the same period data is collected from the RDS and locCRN, 2016/17. This chapter reports the document review findings on resources, sharing and collaboration and visually displays which parts of the NIHR infrastructure have been involved in cross-regional joint working.

Chapter 5 - Research Design Service PPI provision, knowledge-sharing and collaboration

Here the findings from the in-depth interviews with RDS PPI leads are reported in a within-case analysis. The RDS PPI resources and support offered to clients consulting the service are described. From an in-depth analysis the barriers and enablers to cross-regional and national knowledge-sharing and collaboration are reported.

Chapter 6 – Patient and public involvement in NIHR funding panels

This chapter presents data from the interviews with public members of the selected NIHR funding panels. It describes the experiences of public members in preparing for and undertaking the PPI funding panel role and identifies ways in which they could be better supported, and the potential to share their expertise with other parts of NIHR.

Chapter 7 - Clinical Research Network PPI provision, knowledge-sharing and collaboration

This chapter follows a similar structure to that described in Chapter 5. It reports the findings from the in-depth interviews with locCRN staff with a responsibility for PPI, in a within-case analysis. The PPI provision and resources are described prior to an in-depth analysis of the barriers and enablers to cross-regional and national knowledge-sharing and collaboration.

Chapter 8 - Cross-case analysis, triangulation and synthesis of data

Three processes of data synthesis are described. The first to collate the resources (physical and human) identified from the RDS, funding panel public members and locCRN data to identify duplication and opportunities for sharing. The second a triangulation of the document review, RDS and locCRN data to match and verify reported sharing and collaboration. The third is cross-case analyses of the RDS and locCRN interview data of a) the regional and b) the national barriers/enablers to knowledge-sharing and collaboration. Drawing upon the conceptual framework models of the barriers and enablers are presented with proposed solutions.

Chapter 9 – Discussion & Conclusions

This chapter discusses how the results link back to the literature review, the key research questions and project aims. It includes suggestions for areas of future research, a brief summary and limitations of the project, contribution to knowledge and concludes with key recommendations.

Chapter 2: Barriers and enablers to knowledge-sharing and collaboration in public sector organisations: literature review

2.1 Introduction

The previous chapter highlighted the growth of the NIHR and in the number staff with a responsibility for PPI, and concern amongst those in a PPI role about duplication of activities. The Going the Extra Mile report recommended sharing good practice and more cross-regional PPI working within and out with the NIHR.[79]

To understand the scope to share and collaborate there was first a need to determine NIHR PPI provision and resources at the design, funding and delivery stages of research. A literature search, conducted at the time of formulating the research questions in 2015, revealed a gap in studies describing the role of salaried PPI staff, how PPI is operationalised, and the support PPI staff provide in a research context. In particular, no studies were identified relating to PPI in an organisational context. Regarding the role of public contributors on funding panels, one study was identified from the Patient-Centered Outcomes Research Institute (PCORI) that describes their new initiative of including patients and other non-scientific stakeholders in the review of funding applications.[15] Those new to the review role are supported by a reviewer mentor programme and are allocated a mentor with review experience who provides guidance and advice on an ad hoc basis. Earlier studies focused on the level of involvement of public contributors in funding decisions[109] and their impact when involved.[110]

Regarding the second question, ‘What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?’, a preliminary search revealed some papers on the barriers/enablers to knowledge-sharing and collaboration in public sector organisations, but nothing formally documented about NIHR PPI and, to this point, the views and experiences of relevant staff on this matter have not been explored. This lack of published studies reinforced the view that this was a fruitful area of exploration the findings of which would fill this gap in the literature. A decision was made to focus the literature review on the barriers/enablers to knowledge-sharing and collaboration in public sector organisations to determine what could be learned from the literature and applied to this project.

The importance of knowledge-sharing and collaboration in private and public sector organisations has been documented. Tacit knowledge– the experiential knowledge gained over time - in particular is a valuable resource and ‘the performance of any organisation, private- and public-sector, is substantially dependent upon the knowledge of its employees’ (p4).[111] When employees retire or move to another workplace this critical knowledge is lost.[112] The benefits of public sector knowledge-sharing include: a greater ability to problem-solve and co-ordinate across agencies[113]: the opportunity to create communities of practice[113-115]; and to promote innovation and reduce duplication.[116] Through collaboration, public sector organisations can combine assets and power, maximise resources and increase efficiency and quality.[117] Despite these benefits, facilitating knowledge-sharing and collaboration across organisations is not without its problems.[118, 119]

The substantive literature exploring knowledge-sharing and collaboration is from the private sector.[120-124] Despite a smaller evidence base, this review draws upon public sector research. As Henttonen states ‘the uniqueness of the public sector suggests that it might be unwise to directly apply the results of studies conducted in private sector firms to public sector organisations and that there is a need to conduct empirical investigations of public organisations’ (p759).[125] This ‘uniqueness’ could refer to individual motivations for sharing and collaboration in the public sector, as non-profit making organisations, to those in the private sector where financial gain is the primary goal and competition is a key factor.[126] The private and public sectors have different organisational structures which are in and of themselves potential barriers to, or enablers of, knowledge-sharing and collaboration. The public sector literature on knowledge-sharing and collaboration refer to either intra- or inter-organisational barriers/enablers (a small number explore both). In the context of this project, although the NIHR has many component parts, it is a single organisation and places an emphasis on being ‘one’. Therefore, the intra-organisational literature is of greater relevance and will be the focus of this review.

This review informed the development of the conceptual framework for this project and was used to guide the interpretation of the case study data (Chapter 8). The specific question this literature review will address is:

- What are the individual and organisational enablers and barriers to public sector intra-organisational knowledge-sharing and collaboration?

This chapter begins with definitions of knowledge and collaboration, followed by a description of the methods, a review and critique of the literature, firstly pertaining to knowledge-sharing and then to collaboration. The chapter concludes with a discussion of the findings and a conceptual framework of knowledge-sharing and collaboration barriers/enablers.

2.2 Definition of the concepts

2.2.1 Knowledge

Information and knowledge are often used interchangeably in the literature. Here the following definitions are adopted: information is processed data, easily shared and in written format; and knowledge is gained through learning and experience and is more difficult to share. Knowledge can be explicit or tacit. Explicit knowledge can be codified, stored and shared without the continued involvement of an individual. Tacit knowledge, coined by Polanyi in 1966[127], is defined as 'know how' acquired through experience.[128] It is difficult to articulate and codify, and requires involvement of the knowledge-holder. In the context of this project the focus is sharing explicit and tacit knowledge, rather than information or processed data. An example scenario of explicit and tacit knowledge is an NIHR PPI event. Explicit knowledge would relate to the organisation of the event, how relevant invitees were identified and invited, facilitation of the event and the requisite skills. This explicit knowledge is sharable though may not necessarily be in document form. Tacit knowledge would be the experience PPI staff gained from planning and running the event, what they learnt and what might they do differently if they were to repeat the task. This tacit experiential knowledge is more difficult to share with others in a formal way and is likely to build and increase over the years. In this project, and from an understanding of NIHR PPI staff, the assumption is that both explicit and tacit knowledge-sharing would be of the greatest benefit and, with collaboration, will be the focus of this review. Studies that refer to information-sharing will be included if the information is deemed to be knowledge.

2.2.2 Collaboration

Collaboration, sometimes referred to as joint- or partnership- working, is defined variably in the literature.[129] This review adopts Whitford's definition: 'Intra-organizational collaboration is when people within an organization work together to achieve common goals through communicating and sharing strategies, knowledge, resources, and information' (p323).[130] Collaboration does not merely happen and requires the optimum pre-conditions (antecedents) and processes of governance, administration, organisational autonomy, mutuality, and norms of trust and reciprocity.[119]

Although collaboration is likely to involve knowledge-sharing there is a distinction between the two concepts. Collaboration requires joint working toward a shared goal and acknowledgement of mutual benefits. Knowledge can be shared in isolation or as part of a collaboration but in itself, and in the absence of a shared goal and mutual benefits, will not lead to collaboration.[119]

Another dimension of collaboration to be considered is who within an organisation is involved. This can be between staff and their superiors (vertical interpersonal), between those in the same team and the same level/grade (horizontal interpersonal) and across different teams (interwork collaboration).[130] This is important to consider in exploring barriers and enablers to collaboration, particularly due to the diversity of NIHR staff with a PPI role.

2.3 Methods

2.3.1 Search strategies and data sources

Separate search strategies were developed (Table 2.3-1) and tested to ensure key articles were included. Searches (all years) were conducted in Web of Science to capture the organisational literature. Keyword searches of appropriate journals and manual searches of reference lists of relevant papers were also conducted. Alerts were created to identify new relevant literature published over the course of the project.

Table 2.3-1 Search Terms

Information sharing
TOPIC: ("information sharing") *AND* TOPIC: ("public sector")
Databases= WOS, KJD, MEDLINE, SCIELO Timespan=All years
Search language=English

Knowledge sharing
TOPIC: ("knowledge sharing") *AND* TOPIC: ("public sector")
Databases= WOS, KJD, MEDLINE, SCIELO Timespan=All years
Search language=English

Collaboration
TOPIC: (TOPIC: ((collaboration) AND TOPIC: ("public sector")))
Databases= WOS, KJD, MEDLINE, SCIELO Timespan=All years
Search language=English

2.3.2 Inclusion and exclusion criteria

Articles published in English, of studies conducted in the public sector, and exploring/measuring the barriers/enablers to knowledge-sharing and collaboration *within* an organisation (intra-organisation, inter-department) were included (Table 2.3-2).

Several articles explore *inter-professional* collaboration, primarily between doctors and nurses. One often cited barrier to inter-professional collaboration between doctors and nurses is the power differences.[131, 132]. For this reason, studies focusing on doctor-nurse collaboration were excluded. Articles focusing on intra-professional collaboration in a health-care setting, for example, between nurses, multi-disciplinary teams or doctors from the same or different speciality, were included.

Table 2.3-2 - Inclusion and exclusion criteria

Inclusion	Exclusion
Studies exploring intra-organisational barriers/enablers to knowledge-sharing and collaboration	Studies exploring inter-organisational barriers/enablers to knowledge-sharing and collaboration
Work related explicit and tacit knowledge	Information/knowledge about specific individuals, e.g. clients
Collaboration between multidisciplinary or intra-disciplinary teams	Collaboration between individuals from different disciplines, e.g. doctors and nurses

2.3.3 Screening and data extraction

Citations were downloaded to EndNote and the titles and abstracts sifted for relevance. Full papers were accessed when the relevance of articles was unclear. NVivo[133] was used to facilitate the review process and extract data.

Knowledge-sharing - From an initial scoping review, a large number of public sector studies measured one or two barriers/enablers proven to impact upon private sector knowledge-sharing. As argued earlier, this is problematic as findings from one setting may not be applicable to the other. The qualitative studies identified in the search employed an open exploration of barriers/enablers to knowledge-sharing, rather than pre-determined ones from private sector research. For this reason, a framework of barriers/enablers was developed from the public sector qualitative studies to filter the quantitative studies for inclusion. In this way it was possible to examine how the barriers/enablers identified qualitatively perform against knowledge-sharing when measured quantitatively.

2.4 Barriers and enablers to public sector intra-organisational information/knowledge-sharing

274 citations were identified resulting in 36 included intra-organisational knowledge sharing papers (Figure 2.4-1) published between 2001 and 2020. Research settings

included governmental, public sector, higher education and health-care organisations. Thirty studies employed quantitative (surveys), six were qualitative and one was mixed methods. Details of included studies are provided in Table 2.4-1.

Figure 2.4-1– Flow chart of citations - barriers and enablers to knowledge/information sharing in the public sector

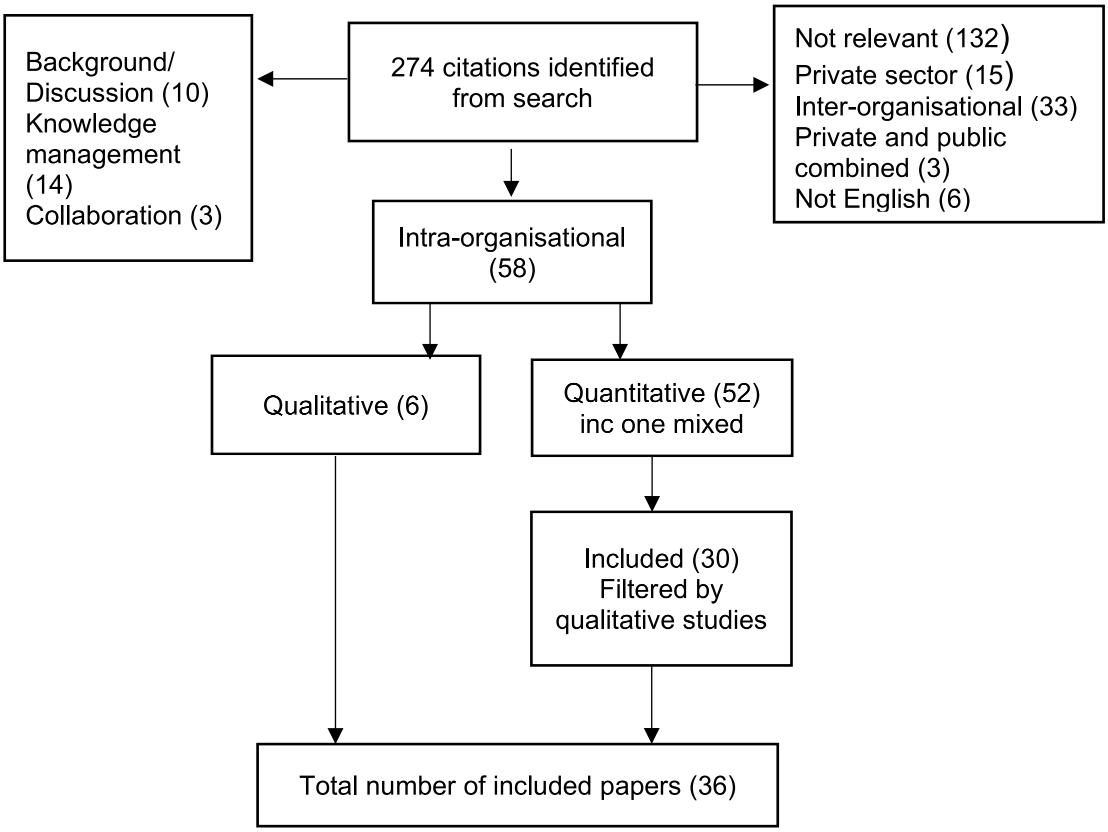


Table 2.4-1 - Included papers for barriers/enablers to public sector intra-organisational knowledge-sharing

Author	**Year**	**Country**	**Organisation**	**Population**	**Design**	**Methods**	**Respondents/ participants**
Bock	2002	Korea	Public sector (4)	Staff from 75 departments	Quantitative	Survey	467
Kolekofski	2003	USA	University (1)	Faculty and support staff	Quantitative	Survey	85
Bardzki	2004	UK	Local authority	Design team division	Quantitative	Survey	38 (estimated)
Willem	2007	Belgium	Government (90)	Range of staff	Quantitative	Survey	358
Gammelgaard	2007	Denmark, Bulgaria, Russia & Turkey	Public and private (7)	Staff from four government organisations	Quantitative	Survey	1535
Armoogum	2010	UK & Germany	Health-care sector	Radiotherapy physics teams	Qualitative	Interviews	61
Gambarotto	2010	Italy	University (1)	Information & Communications Technology staff	Quantitative	Survey	58 (estimated)
Seba	2012	Dubai	Police Force	Police Officers	Qualitative	Interviews	15
Seba	2012	Dubai	Police Force	Range of staff	Quantitative	Survey	319
Amayah	2013	USA	Academic institution	Professional to service maintenance	Quantitative	Survey	439
Fullwood	2013	UK	Universities (11)	Academics	Quantitative	Survey	230
Kim	2014	US	Federal government	Range of staff	Quantitative	Survey	222,959
Boateng	2016	Ghana	Public sector (1)	District Assembly staff	Qualitative	Interviews	23
Park	2015	Mongolia	Central government (6)	Range of staff	Quantitative	Survey	220
Gardiner	2016	Australia	Rail Services	Engineers & designers	Case Study	Interviews	18
Ignacio Castaneda	2016	Columbia	Public sector (1)	Managers, professionals & advisors	Quantitative	Survey	188
Muqadas	2017	Pakistan	Universities (3)	Management & teaching	Qualitative	Interviews	40
Muqadas	2016	Pakistan	Universities (3)	Teaching and research	Quantitative	Survey	216
Vong	2016	Cambodia	Public Sector (70)	Range of staff	Quantitative	Survey	105

Author	**Year**	**Country**	**Organisation**	**Population**	**Design**	**Methods**	**Respondents/ participants**
Tahir	2016	Malaysia	Higher Learning Institutions (4)	Instructors & teachers	Mixed	Survey & Interviews	212 & 4
Bibi	2017	Pakistan	Universities (6)	Academics	Quantitative	Survey	369
Fullwood	2017	UK	Universities (number not stated)	Academics	Quantitative	Survey	367
Li	2017	China	State owned organisations (number not stated)	Managers & administrators	Quantitative	Survey	428
Masood	2017	Pakistan	Hospitals (number not stated)	Nurses and doctors	Quantitative	Survey	587 nurses and 164 doctors
Tamta	2017	India	Public sector banks (42 branches)	Junior & middle level managers	Quantitative	Survey	294
Tuan	2017	Vietnam	Public utilities (3)	Range of staff	Quantitative	Survey	759
Kim	2018	Korea	Public sector (number not stated)	Range of staff	Quantitative	Survey	500
Basit-Memon	2018	Pakistan	NHS (3)	Doctors & nurses	Qualitative	Interviews	75
Dey	2018	India	Public sector (number not stated)	Managers	Quantitative	Survey	231
Amber	2019	Pakistan	Federal Ministries (5)	Executives	Quantitative	Survey	509
Garcia-Sanchez	2019	Spain	University (1)	Research teams (87)	Quantitative	Survey	283
Rohim	2019	Indonesia	Public Sector agencies (number not stated)	Managers	Quantitative	Survey	254
Hendryadi	2019	Indonesia	Local authorities (11)	Range of staff	Quantitative	Survey	371
Kipkosgei	2020	Kenya	Public organisations (3)	Range of staff	Quantitative	Survey	255
Raza	2020	Pakistan	Higher education (15)	Non-academic	Quantitative	Survey	273
Raza	2020	Pakistan	Higher education (6)	Academic	Quantitative	Survey	278

In the next section the included qualitative studies will be described and the key barriers/enablers to knowledge-sharing they elicited. In Section 2.4.2 the impact of these barriers/enablers on knowledge-sharing will be discussed as determined in the included quantitative studies.

2.4.1 Qualitative studies

Six qualitative studies explored barriers/enablers to knowledge-sharing (KS) in the health-service sector, police force, district assembly, rail services, and university. The qualitative component of one mixed methods study has been excluded from this section as only four interviews were conducted.[134] However, where the interview data illuminate the quantitative findings they will be reported in Section 2.4.2. Knowledge, in the context of these studies was tacit knowledge[135-137], tacit and explicit knowledge[138, 139] and one did not specify.[140] Sample sizes ranged from 15 to 75. Table 2.4-2 outlines the population and questions/areas of exploration in each study.

Table 2.4-2 - Qualitative studies – areas of exploration regarding public sector intra-organisational knowledge-sharing

Author	**Population**	**Design**	**Methods and n=**	**Questions/Exploration of knowledge-sharing**
Armoogum 2010	UK & Germany - Radiotherapy physics teams -23 NHS trusts UK/Not stated for Germany	Not stated	Peer surveys n=61	• Spatial factors • Social relationships • Motivation to share knowledge • Channels for knowledge sharing and support for new members of the community of practice.
Seba 2012	Dubai - Police Officers	Single case study	Semi-structured interviews n=15	• What does the organisation do to encourage employees to exchange and share knowledge? • What difficulties, if any, does the organisation face in encouraging employees to exchange knowledge?
Boateng 2016	Ghana - District Assembly staff	Single case study	Semi-structured interviews n=23	• What will make you share what you know with your co-workers? / Under what circumstance would you share your knowledge? Explain.

				• What do you look in for in your co-worker before you share your knowledge with him or her? Explain. • What will prevent you from sharing what you know to your co-worker? Explain. • What will affect your decision to share knowledge with your boss or colleagues?
Gardiner 2016	Australia - Rail Services engineers & designers	Single case study	Semi-structured interviews n=18	• Tell me about your work here • Tell me about a situation where knowledge sharing worked well; • In your opinion, why did it work well? • Who are you most likely to share your new ideas with, why is that? • What are the most important influences on how knowledge is shared around here? • To what extent would you say your own knowledge sharing is sometimes influenced by how you view the other person?.
Muqadas 2017	Pakistan - University management and teaching 3 universities	Not stated	Unstructured interviews n=40	• What is the orientation of knowledge hoarding in your organisation? • What is the orientation of knowledge sharing in your organisation? • What are the challenges for knowledge sharing practices? • Why the employees of public sector hoard the knowledge in universities? • What are the initiatives that should be taken to eradicate knowledge hoarding culture? • What are the factors that can contribute to foster knowledge sharing practices?
Basit-Memon 2018	Pakistan – Doctors, nurses and senior management - 3 hospitals	Multiple case study	Semi-structured interviews n=75	• Status of knowledge sharing • Knowledge sharing processes • Antecedents/barriers to knowledge sharing

The studies highlighted barriers/enablers in KS ranging from benign factors, such as the physical setting, to more serious ones, for example, deep-rooted cultural differences. Table 2.4-3 summarises the key factors identified from this qualitative review divided into organisational and individual barriers/enablers.

Table 2.4-3 - Factors identified from the qualitative studies

Organisational
Organisational culture – culture of sharing, culture of value and respect for staff [137, 138, 140]
Organisational structure[138]
Leadership/management[138-140]
Format of, and setting for, knowledge sharing[135]
Time[138, 140]
Rewards[136]
Individual
Trust[137-140]
Threat[136, 139, 140]
Reciprocity [136, 137]
Confidence to share[135]
Organisational commitment [136, 137]
Job satisfaction – motivation and involvement[136]
Social relationships [135-137]
Incentives/rewards[136]
Assessment of knowledge recipient [137, 139]

Organisational factors

Organisational culture

As a barrier/enabler to knowledge-sharing culture could be pervasive and organisation-wide[137, 138] or specific to workplace sub-cultures[140]. A culture where government sector staff - and the organisation - respect and value each other was said to impact positively on knowledge-sharing.[137] Interviewees said that being undermined, treated with disdain and not considered an equal – by co-workers and management - would prevent them from sharing their knowledge. In the police force, the findings suggest a widespread lack of understanding of, and commitment to, KS and what was expected of individuals.[138] In the study conducted in three health care settings interviewees reported some workers deliberately switched to a language understood by their own cultural group when sharing more specific knowledge, or when communicating in a multi-ethnic open forum used hidden codes only their own group would understand.[140]

Organisational structure

One study identified the organisational structure, particularly a hierarchical structure, where each department has sections or divisions, to inhibit contact between staff in other departments/sections and reduce KS opportunities.[138] Staff looked to their managers for information or knowledge rather than their peers. Some managers viewed departmental meetings as an arena for KS whereas for the lower rank officers the meetings were where they received orders.

Leadership/management

Leadership/management was identified as a barrier/enabler to KS in three studies.[138-140] In the health care sector and police force, managers were considered key in encouraging KS by motivating[140] and empowering staff, building trust, and raising awareness of organisational goals.[138] This motivation was crucial because of the inherent risks in KS.[140] These risks related to negative past experience of others using the knowledge for their own gain. Managers should also support employees to share knowledge, for example ensuring staff have time and resources (i.e. seminar rooms and equipment) and offering financial and non-financial rewards.[140] Management not supporting KS in this way led some police officers to believe their managers either did not understand or lacked commitment to KS.[138] In the universities a lack of organisational support was reported to lead to knowledge-hoarding.[139]

Physical setting and format of knowledge-sharing

The physical setting and the format of KS was cited as a barrier in one study. Physical settings, for example open-plan offices, were more conducive to KS and led to increased interaction between individuals than those where the staff were spread across several hospital trusts.[135] There was a preference for more informal means of KS as staff felt less inhibited to ask questions, but those from larger departments and at a more advanced stage in training preferred a more formal or a mix of ways to share knowledge.

Time

In the police force and health care sector, a lack of time for KS was cited as a barrier[138, 140] As demonstrated above, this was sometimes linked to leadership/management and the view that if KS was important, managers would allow staff the time for KS activities.[138] Time was also needed to advance knowledge, for example, to keep up to date with key literature; without this some lacked confidence to share.[140] Some had little time to engage in KS activities due to their heavy workload.[140]

Rewards

Only one study reported extrinsic rewards as a motivator for KS. In the rail service study designers/engineers received recognition for their achievements.[136] This ranged from an email to acknowledge a job well done, to local celebrations, to an awards process. For the awards, employees are encouraged to nominate co-workers. This attention from the organisation was appreciated by the workforce and at a departmental level encouraged employees to build relationships and engender mutual respect.

Individual factors

Trust

Trust was the individual barrier/enabler to KS most commonly identified.[137-140] Government and health care sector workers believed knowledge to be an asset and they were more likely to share with someone they trusted.[137, 140] In the university setting, a culture that fosters trust was said to motivate employees to share both tacit and explicit knowledge within and beyond the boundaries of the organisation.[139] Only two of the studies delved into *why* trust was a barrier and found it was related to uncertainty around the recipient's intentions regarding the knowledge[140] and to whether their contribution would be valued by others.[138]

Threat

Threat was identified as a factor that impacted on KS in universities[139], health care settings[140] and the rail service[136]. In the universities knowledge was regarded a personal asset and to share was a threat to their power, influence and authority, and value to the organisation.[139] Sharing was believed to impact upon opportunities for promotion and some staff were protective of their contacts with others outside of the organisation, for example co-authors on publications.[139] An unwillingness to share in health care settings was based on past negative experience, for example, where colleagues have used another person's knowledge to their own advantage without acknowledging the source[140] Similarly, in the rail service interviewees identified one colleague who was unwilling to share knowledge because of past experience when he believed others had negatively affected his career progression.[136]

Reciprocity

Reciprocity in KS was a barrier/enabler in the studies conducted with government and rail service employees.[136, 137] Government employees would determine if there was a willingness on the part of a co-worker to share in return before sharing.[137] This was the same for design/engineering staff, but also some were motivated to share because they required knowledge from another immediately or thought they may do in the future.[136]

Confidence to share

A lack of confidence was a barrier to KS in the two studies conducted in health care settings.[135, 140] Most of the radiotherapists were highly motivated to share knowledge; where there was a reluctance this tended to be those working in large departments who lacked confidence to share knowledge.[135] For nurses, doctors and administrators a lack of time to keep up to date with the literature led to a lack of confidence in KS.[140]

Organisational commitment

Two studies identified organisational commitment as a KS barrier/enabler.[136, 137] Government employees were motivated to share knowledge by the belief it would lead to greater organisational success: sharing knowledge was considered to be for the greater good, and knowledge hoarding selfish and an impediment to the organisation's growth and goal achievement.[137] In the rail service sector KS was more likely to occur when employees' interests converged with those of the organisation.[136]

Job satisfaction & Intrinsic rewards

The study conducted with rail service engineers/designers highlighted two barriers/enablers not found in the other qualitative studies which the authors reported as precursors for KS. The first was job satisfaction which was linked to dedication for, and emotional engagement with, the work and a pride in what they do.[136] The second was the importance of intrinsic rewards, such as intellectual stimulation, and the opportunities for innovation through KS.[136] In education, academics' beliefs that KS would have positive personal benefits had a impact on KS attitudes.[141]

Social relationships

Social relationships with co-workers were identified as an enabler in three studies in government, rail service and health care.[135-137] In a government context the authors merely reported some staff were more likely to share with colleagues who are also friends.[137] Rail service workers considered good personal relationships to be facilitatory for KS.[136] They were also selective in the type and amount of knowledge they shared with someone they do not get along with or who has mistreated them in the past. In a health care setting over half of the radiotherapists interviewed thought social relationships were necessary for KS primarily as it reduced inhibitions in asking questions.[135]

Assessment of knowledge recipient

A process of assessing the recipient before KS was highlighted in one study.[137, 139] Government employees would assess whether the potential knowledge recipient had the requisite level of education and understanding to make it worthwhile sharing.[137]

Summary

There are issues with the quality of some studies methodologically and in the reporting. The exploration was not always truly as open as the study aims suggest. In the study of university employees, the primary focus on hoarding behaviours is to the detriment of responses to the more general question about attitudes to KS which are skimmed over.[139] Also, the subtleties of KS appear to be lost in the exploration of hoarding; individuals may not consciously hoard knowledge but believe they have little of worth to share. The area of exploration for another is based on articles from a special issue journal none of which are based upon research in a public sector setting, and most from experiments with students.[135] The same study is described as qualitative, with five structured questions described as ‘open’ and potential responses as yes/no/unsure. They do, however, state ‘The interviewee was able to diverge to pursue an idea in more detail.’ (p18).[135]

In reporting the findings, in one study there is an absence of information about the numbers of doctors, nurses and administrative staff interviewed, and the spread across the three organisations.[140] Whether the KS problems are the same for each professional group, and if experience differs depending on the organisation is not reported. It is also unknown whether it is KS across and/or within professional groups that is problematic. The study conducted of employees from three universities provided summarised grouped views for each theme rather than original quotations.[139] This made it difficult to gain a sense of strength of feeling for each of the barriers/enablers. Finally, in the study of government employees, the factors as presented were neither a barrier nor an enabler but illustrated the circumstances where KS would happen.[137] Level of experience was reported to be an enabler of KS yet the authors did not provide evidence that those with less experience were reluctant to share knowledge.

Despite some of the flaws in the qualitative studies the factors identified provide a framework for selecting the quantitative studies of public sector KS. They also illustrate how certain barriers/enablers are linked or contingent on others, for example trust, reciprocity, threat and social relationships. In the next section the selected quantitative studies are reviewed to determine the impact of these factors on KS.

2.4.2 Quantitative studies

Thirty quantitative papers measured the impact of one or more of the KS barriers/enablers identified from the qualitative studies. None were identified that measured the 'setting' or 'assessment of the knowledge recipient' barriers/enablers.

The quantitative papers covered three levels of evidence. The first where scales measured both knowledge-sharing *behaviour* (KSB) and specified factors (barriers/enablers), which were then compared statistically.[126, 142-156] The second measured respondents' knowledge-sharing *attitudes* and *intentions* (KSI) against the factors, or whether the factor was a predictor/determinant of the behaviour.[134, 141, 157-

[160] The final level of evidence was a questionnaire without scales, where respondents were asked whether a specific factor was a barrier/enabler to KS, either in their opinion or experience.[161-163] There was considerable variation in the measures of barriers/enablers used (Appendix E & F). Sixty different instruments were used to measure organisational barriers/enablers (Table 2.4-4). Only a small number of studies used the same instrument. Five new measures were developed specifically for the study.

Table 2.4-4 - Measures of barriers/enablers – organisational factors

Item/factor	No of studies measured item	No of different measures used across studies	No of studies used same measure (author of measure)	Measure developed for purpose of the study	Not specified
Culture	8	12	0	0	1
Structure	6	5	3 (Kim 2006) 2 (Gold 2001)	0	
Leadership	12	14	2 (Riege 2005)	1	
Incentives rewards	16	27	2 (Bock 2005)	3	1
Time	2	2	0	1	

There were 48 different measures for the seven barriers/enablers to individual KS (Table 2.4-5). Only a small number of studies used the same instrument. Five new measures were developed specifically for the study.

Table 2.4-5 - Measures of barriers/enablers- individual factors

Barriers/enablers	No of studies measured barrier/enabler	No of different measures used across studies	No of studies used same measure (author of measure)	Measure developed for purpose of the study
Reciprocity	2	2	0	1
Trust	12	14	2 (Chow 2008) 2 (Arnold 2000)	1
Power & threat	4	5	0	2
Organisational commitment	8	10	2 (Bock 2005)	0
Social networks & relationships	5	10	0	1
Job satisfaction	2	4	0	0
Confidence	3	3	0	0

The variation in the measures may be attributable to differing definitions of the barriers/enablers. As this variation may have implications when comparing the studies, these differences will be highlighted when each barrier/enabler is discussed.

Four types of organisations were identified: governmental, for example local authority, ministries, federal agencies[126, 143, 147, 153, 161, 162, 164]; public sector[144-146, 148, 151, 152, 155-157, 159]; educational, such as universities and colleges[134, 141, 142, 149, 154, 158, 160, 163, 165] and health care.[150] In some studies, governmental organisations were defined as public sector.

Organisational culture

Organisational culture is acknowledged as fundamental to the performance of an organisation. As many aspects of this concept 'are intangible and cannot be seen' (p493)[166] it is a difficult to define. In the 1980s Edgar Schein developed a model of organisational culture with a strong emphasis on values and shared assumptions.[167] This model of organisational culture is said to imply

> 'that culture embodies shared values, beliefs and assumptions that are deeply ingrained in an organisation's traditions, and influence how an organisation thinks and feels, wrapped up as the 'how we do things around here' maxim.' (p3) *[168]*

Possibly because of the nebulous nature of organisational culture, the public sector studies varied in the constituent elements of the concept. For example, in one it encompassed affiliation to institution, autonomy, leadership, organisational structure, values and technology.[141] In another the associability element of social capital - defined as the 'willingness and ability of employees to define collectively goals that are enacted collectively' (p137)[152] - fitted with Schein's definition.

Organisational culture had no, or very little, impact in the public sector[151, 152] In a survey of UK local authority workers, organisational culture was reported as a KS barrier.[161] Interviews with six survey respondents found the existence of a blame culture, fear of reprimand, and the presence of sub-cultures as KS barriers.[161] The exact nature of these sub-cultures was not reported in the paper. Across educational settings the findings varied. These studies measured organisational culture against attitude to[141], as a predictor of[134], or motivator to KS[142], but this is unlikely to be the reason for contradictory findings. One explanation could be the types of staff these studies surveyed: some focused on teaching staff[141], and another on researchers, management and administrative staff[142], and these professional groups could have very different localised cultures with regard to KS. One interesting finding from the interview data with technical college teachers and instructors was KS was not always deemed part of the workplace culture and there was a preference for completing tasks they believed were part of their role and 'beneficial compared to knowledge-sharing with other colleagues' (p484).[134]

Organisational structure

The factor with the most consistent findings across all settings was organisational structure. Unlike the private sector which has three main types of organisational structure - functional, divisional and matrix - the public sector tends to have a hierarchical structure with a clear chain of command. In public sector and educational organisations the structure was found to promote individualistic rather than collective behaviour and this impacted negatively on KS.[159] A hierarchical structure in government had a negative association with KSB. When compared to government KS was more prevalent in NGO and not-for-profit organisations which consisted of smaller less formal work units.[144]

Leadership

Leadership was a frequently measured barrier/enabler to KS.[134,142, 143, 159-161, 144; 134, 147, 148, 150, 169] How leadership was measured was not always stated[143] and across the papers the components of leadership differed.

The style of leadership had a positive impact on knowledge-sharing in the public sector[147, 148, 169] and health care setting where it led to psychological empowerment of nurses and facilitated KSB.[150] For teachers and instructors leadership was a predictor of, and played an important role in, encouraging KS practices, yet the four qualitative interviews with teaching staff highlighted a lack of managerial support and encouragement.[134]

Where leadership pertained to support and encouragement for KS it influenced the attitudes and intentions in the public sector.[159] In government, there was a weak positive relationship between leadership and KS[143] and the managers' support of an information management system, rather than the individuals, impacted upon KS.[144] In Scottish local authority, most survey respondents reported managers' lack of encouragement a barrier to KS.[161]

In educational organisations the results again were mixed, indicating a more complex picture. KS was contingent on a number of factors and not leadership alone, such as a lack of trust in managers' judgement and favouritism towards certain staff[160] and organisational commitment.[142]

Incentives and rewards

Incentives and rewards can be extrinsic - bonuses or an increase in salary but could also be the chance of promotion – intrinsic - acknowledgement for an achievement or the opportunity for professional development - or social - strong relationships with co-workers and the consequential benefits.[170]

Nine studies in government, public sector and educational settings measured the relationship between KS and extrinsic and/or intrinsic rewards and incentives.[126, 143, 144, 151, 155, 157, 159, 162, 164] Social rewards were included within intrinsic rewards rather than as a separate construct in the studies.

In the public sector, extrinsic rewards had no impact on KSB[144, 162] or attitudes[157, 159], but were found to be a mediating factor between emotional intelligence and KSB.[151] For government and public sector employees, rewards including training and development had a positive impact on KS, as staff felt they were valued by the organisation.[164] However, another study found a lack of incentives was associated with a lower level of identification with the organisation, and less engagement in activities where KS could occur.[126] In government, extrinsic rewards such as performance-based promotion had an impact on KSB[143] as did remuneration but this could be contingent on organisational structure.[155]

The findings were contradictory across the studies conducted in an educational setting where rewards were a significant predictor of KS[134], had no impact on KSB[149] or were believed to *lead* to extrinsic and intrinsic rewards for teaching and research staff.[160] For a mix of university employees there was a significant *negative* relationship between personal benefits, rewards and KS.[142] The authors' conclude the costs of sharing may outweigh the benefits, and rewards may have an adverse effect on staff relations.

Time

Sharing knowledge is not a passive behaviour. It involves time and energy, and there can be an element of risk.[118, 140] In a literature review of information/knowledge sharing Yang et al said 'before sharing tacit information and knowledge, a contributor may need to spend significant time and effort to articulate, prepare and arrange the information' (p168).[171] Sharing may not be a one-off activity and could lead to further requests.[171] When KS is not part of the organisational culture it can be considered extra work.[140]

Time and confidence to share were not explored in many studies. For the former, as might be expected, a lack of time had a negative influence on attitudes to KS in one public sector study.[159] However, in education there was only a weak relationship between time constraints and KS.[134]

Confidence

None of the quantitative studies included a factor termed ‘confidence’. However, three measured self-efficacy and degree of courage.

In the public sector, self-efficacy had a stronger relationship with KS *intention* than *behaviour*[145] and lower self-efficacy impacted on staff’s confidence to engage with a newly developed community of practice (CoP) which in turn had an impact on KS.[163] In the educational sector one study measured confidence as ‘degree of courage’ - ‘an individual’s ability to express his or her opinions without fear’ (p460) – which had a moderating effect on the relationship between motivation to share and sharing activities.[142]

Organisational commitment

Organisational commitment is defined as ‘the relative strength of an individual’s identification with and involvement in a particular organization’ (p226).[172] The majority of studies identified were conducted in the public sector. Organisational commitment was defined in a variety of ways.

Within the public sector organisational commitment had a positive significant relationship on KSB[144] and ‘expected contribution’ - which has attributes of organisational commitment - was a determinant of KS.[157]. In a similar vein, ‘organisational citizenship behaviour‘ - employees going above and beyond and promoting the organisation more widely - had a mediating role in the positive association between leadership and KSB.[148] In government, Public service motivation (PSM) - commitment to public values and attraction to public service – was positively associated with KS.[152] Only one study, which was a mix of public sector and government organisations, reported commitment to the organisation had no impact on KS.[126] The lower level of commitment in government employees identified, was surmised to be because ‘the end product was less definable’ (p598).[126]

Only one study measured the impact of organisational commitment on KSB in educational settings and found a significant positive association between the likelihood of university academics staying with the organisation and higher level of KSB.[149]

Job satisfaction

Job satisfaction impacted significantly on KSB in university academics.[149] With a slightly broader focus, there was a positive association between work engagement and KSB in junior and middle-management staff in state-owned banks.[151] The work engagement scale included items to measure the level of enthusiasm, dedication and absorption individuals had in their job.

Threat and power

As stated earlier, knowledge, particularly tacit knowledge, is recognized as a valuable commodity to private and public sector organisations.[111] For individuals the risks of sharing knowledge could be a loss of standing or value of the individual within the organisation and damage reputationally if the knowledge is not considered of worth.[173]

The threat of sharing and the power gained from retaining knowledge impacted on KS in government.[153] Knowledge was power and staff were concerned their value to the organisation would be diminished if they shared. There was some interplay between power games and organisational structure where sharing was viewed negatively in certain structures. The majority (87%) of Scottish local authority employees agreed the belief that knowledge is power was prevalent among staff in their department and this impacted greatly on KS.[161] The one public sector study (which included some governmental organisations) revealed a complicated picture where power games could increase KS as it led other employees to establish informal groups where they would feel safe to impart their knowledge.[126]

Of the few studies conducted in an educational setting, where this was measured, the potential loss of power and fear of sharing impacted on KS attitudes.[158] A finding from the qualitative work in the mixed methods study was that teaching staff feared that sharing, particularly with more junior staff, would reduce their standing within the organisation, and they would be viewed as less expert.[134]

Trust

Trust is a recurrent KS barrier/enabler in public sector the literature.[118, 174] It is associated with threat and power, discussed earlier, for example trust that the recipient will not abuse the knowledge.[158]. As might be expected, good workplace relationships, covered in the next section, is another factor linked to trust in KS[118, 174] as is a strong sense of community.[118]

A positive relationship between trust and KSB was demonstrated for employees in central government [143], university academics[149, 175], non-academic staff[176] and researchers.[154] There was a similar picture for trust and KSB[126, 152, 156] and KS attitudes and intentions in the public sector.[159] In another study of university non-teaching staff trust was not a predictor or enabler of KS.[142] This result was unexpected and the authors surmised the reason may be if staff do not perceive the knowledge to be important, or that sharing poses any personal risk, then trust in the recipient may not be needed.

Social networks/relationships and reciprocity

Relationships between co-workers has been described in a variety of ways in the literature, for example as friendships, personal or social relationships and social networks. Reciprocity refers to mutual KS, and as this may overlap with some elements of social relationships these are reported together in this section.

In the public sector/government, social networks led to the sharing of more useful knowledge but not the amount[126] and in government there was no impact on KSB.[143] In contrast, in educational organisations social networks had a positive impact on KSB[139] and was a determinant of KS.[142] Reciprocity was not a determinant of KS[142], yet where it related to the previous behaviour towards the holder of the person requesting the information, had a positive impact on intention to share.[158]

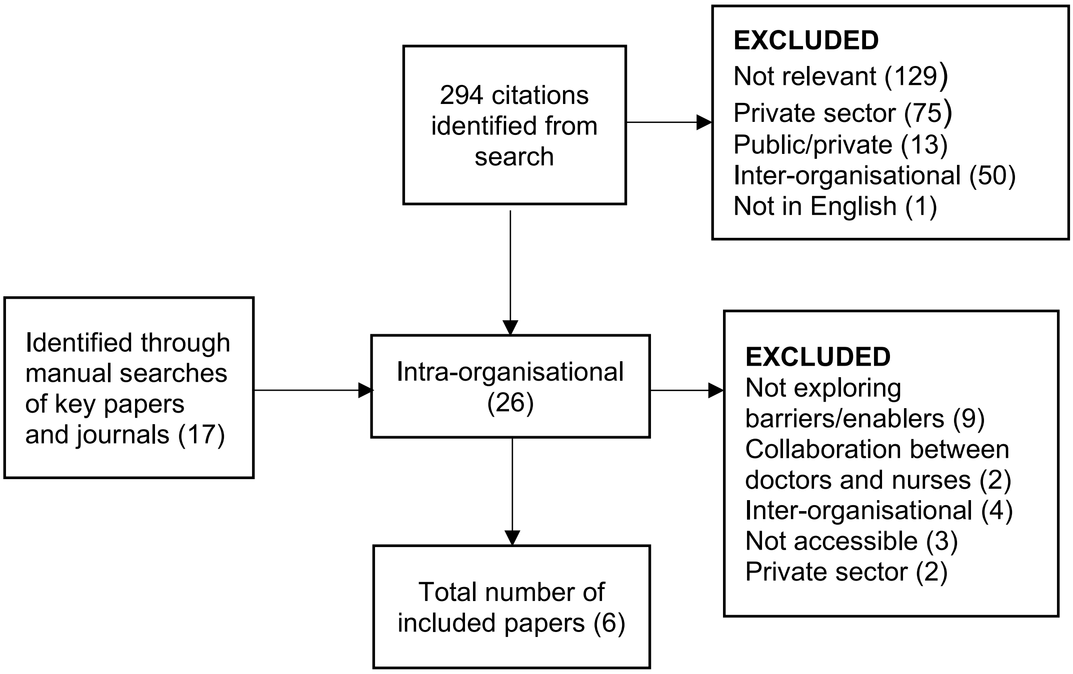
Summary of quantitative studies

The review of quantitative studies has highlighted variation in how the barriers/enablers to knowledge-sharing are defined and measured. Knowledge-sharing itself was sometimes measured as a reported behaviour, an intention or attitude. Because of this, drawing any conclusions about the true barriers and enablers to knowledge-sharing is problematic. There was very little consistency in the findings across, or within, the types of organisations with the exception of organisational structure. The educational setting produced the most inconsistent findings. This could be attributable to the study participants who ranged from administrative, teaching to research. Staff who undertake research, whose continued employment is often dependent upon their success in securing external funding and publications, may have very different reasons for not sharing knowledge compared to someone employed in an administrative capacity.

2.5 Public sector intra-organisational collaboration

Searching only for studies of intra-organisational collaboration led to too few citations. This was most likely due to different terms being used for intra-organisational. A broad search was conducted, and 294 citations were identified through the Web of Science search (Figure 2.5-1) and 17 from searches of relevant journals and the reference lists of key papers. After screening, six papers were included.

Figure 2.5-1– Flow chart of citations - barriers and enablers to collaboration in the public sector



2.5.1 Review of included studies

Six studies were included.[177-182] The settings for these studies included health care, federal government and academia (Table 2.5-1). The studies are presented in chronological order.

The first study is an ethnography undertaken in one UK university to explore how staff, involved in curriculum design, work together to achieve their objectives.[177] Data, from observations of meetings and subsequent reflective discussions with those observed, were collected from 50+ staff members from different programme teams. Several factors impacted upon collaboration. An organisational culture that promoted collaboration and an agreed understanding, beliefs and values between.

Table 2.5-1 - Included papers for barriers and enablers to public sector intra-organisational collaboration

Author	**Year**	**Country**	**Organisation**	**Population**	**Design**	**Methods**	**Respondents/ participants**	**Measures/areas explored**
Diamond	2011	UK	University (1)	Range of staff	Qualitative	Ethnography	50+	Barriers and enablers to collaboration across departmental boundaries.
Rivas	2010	UK	Hospitals (35)	Health professionals and managers	Qualitative	Interviews	43	Personal, departmental and organisational change behaviours and cultures Expectations and experiences of the collaborative intervention Factors affecting change.
Chien	2012	Taiwan	Tertiary Medical Centre	Range of staff	Quantitative	Survey	3462	Sexton's Safety Attitudes Questionnaire (SAQ)
Carter	2014	UK	Hospitals (11)	Range of staff	Qualitative	Interviews & focus group	32	Organisational barriers and enablers to collaboration in the initiative
Moore	2015	Canada	Hospital (1)	Oncology nurses	Qualitative	Interviews	14	Views and experiences of collaboration and the impact of interpersonal, organisational, professional and social factors
Leyenaar	2018	US	Hospitals	Emergency and paediatric health professionals	Mixed methods	Interviews		Barriers and facilitators to interdepartmental collaboration

those involved enabled and enhanced the quality of collaboration. Observations revealed the groups to be fragmented with some members taking a passive role and not contributing to discussions. The authors report these patterns of behaviour were reinforced by the organisation's regulatory system. Barriers to collaboration were a lack of trust and an absence of good relationships between staff.

A survey of staff working in a tertiary medical centre in Taiwan explored the impact of work climate, effective communication, safety culture, job satisfaction, and work pressure on collaboration.[179] Safety culture and job satisfaction were not significant predictors of collaboration. Effective communication - which encompasses ease of communication, two-way communication and understanding of communication channels – was found to be negatively associated with collaboration. The authors conclude this may have been attributable to the measures used. Work climate was the most significant predictor of collaboration. The work climate construct measured the organisation's effectiveness in dealing with problem personnel, training new personnel, and supervising trainees, and the availability of information to enable the individual to carry out their role.

Moore conducted a qualitative case study with 14 Canadian oncology nurses in one centre to understand the factors that influence collaboration.[181] Documentary and interview data were collected. The interview data revealed the enablers to collaboration to be regular face-to-face meetings, longer term social relationships, experience in oncology and strong interpersonal skills. Different modes of communication were used, such as tele-conference and email, but face to face meetings enabled staff to get to know each other personally and professionally and build relationships. Good relationships facilitated collaborative working. Staff found it easier and preferred to collaborate with those they had known for a long time. Perceptions of other staff member's level of experience and knowledge influenced decisions to collaborate and whether they have 'the knowledge they are looking for' (p512). Strong interpersonal skills encompassed respect for others by listening and being open to their views. Finally, personal traits such as a sense of humour, positive outlook, being open and honest were said to be conducive to collaborative working. The barriers were role ambiguity, organisational leadership and multi-generational differences. Role ambiguity presented a barrier between nurses in different roles, for example those working in clinical trials or in an advanced practice role. Some interviewees said being the only person in that role resulted in a feeling of isolation particularly when other oncology nurses lacked an understanding of what the role entailed, and this impeded collaborative working. Organisational leadership encompassed the organisational structure, resources and shared values and goals. Higher management were said to be imposing changes to the structure the nurses found difficult to implement; this, along with a very heavy workload, led to staff burnout and was not conducive to collaboration. The environment was described as hostile, and staff were reluctant to speak out. Management did not provide the resources to enable collaboration, for example time out of clinical or research work for meetings. Multigenerational differences had an impact on collaboration as nurses found it easier to connect with colleagues of a similar age. It was reported that unless there was an existing relationship, older nurses were reluctant to collaborate with younger, new or part-time nurses. Older nurses considered these nurses as ‘less professionally credible’ (p513) and could not see the benefit of collaborating with them. The younger nurses were less keen to collaborate with older nurses because of past negative experiences. Finally, the personalities of the nurses were reported as barriers to collaboration. Nurses did not want to collaborate with colleagues who had a negative attitude and were not open and honest, and who had different goals and values.

Leyenaar[182] conducted a mixed-methods study to identify the barriers and enablers to an inter-departmental quality improvement initiative in 47 US hospitals. The departments of interest were emergency medicine and paediatrics. The barriers and enablers were explored using qualitative methods, namely interviews with (35) collaborative site leaders. Eight domains were found to be key to collaboration in the initiative; four were specific to staff views of the initiative rather than collaboration and therefore are not reported here. The domains of interest are: leadership and support, collaborative culture, departmental structure and resources and inter-departmental relationships. Within leadership and support, giving/not giving time and resources was important to collaboration. Support for collaboration from institutional leaders could have a positive impact on the organisational culture. The authors found some departments did not have a collaborative culture and had different work practices that hampered joint working. There were reports that ‘not everyone was on the same page’ (p219) and some were resistant to collaborating in the initiative. Within the departmental structure and resources domain, siloed working, the size of the department and the power to make changes were barriers/enablers to collaboration. Finally, interdepartmental relationships were important in facilitating collaboration; meeting and talking face-to-face and the involvement of staff who worked across the two departments (boundary spanners) were key to establishing and developing relationships.

Two studies explored the barriers and enablers to collaboration (in service quality improvement initiatives) between multi-disciplinary teams in the UK National Health Service (NHS).[178, 180] Rivas[178] reported intra- and inter-organisational and Carter[180] *inter*-organisational collaboration, though they identified some local barriers and enablers. The focus for collaborative working in Rivas was a multi-disciplinary reciprocal clinical service peer-review, with feedback and the development of action plans. Regarding intra-organisational collaboration, the barriers were a lack of resources and pressures on managers due to the NHS financial climate and organisational changes such as hospital closure or mergers. However, the authors found some teams considered these issues as motivating factors for collaboration. Carter reported on a stroke quality improvement initiative which entailed collaborative shared learning teams from a number of hospital trusts. They found support and collaboration within their own organisation impacted upon cross-organisational joint-working. Barriers and enablers to the implementation of the initiative were management buy-in and the provision of resources, such as dedicated time, for key staff to collaborate, and a champion to promote the collaborative venture. Finally, some senior staff team members did not attend the inter-organisational learning sessions. This left other members of the team, who tended to be lower grade staff, feeling ‘out of our depth’ (p8) and a sense that senior staff considered the initiative of little importance.

Summary

Five of the six studies included employed qualitative methods, therefore most are reported or observed enablers/barriers rather than those measured against collaboration using scales. However, the included studies were rich in their findings. There was no difference in the barriers/enablers identified between the one study conducted in a university and those in a health-care setting, apart from the free-loaders observed in group meetings. In the study of oncology nurses it seems collaborative working was not motivated by altruism, for example to support more junior staff, but by individual gain.[181 105 105 105 105 105 105] The authors also reported past negative experiences and multigenerational differences as barriers to collaboration. As might be expected, personalities played an important role in facilitating collaboration. The two studies focusing on inter-organisational collaboration (i.e. across NHS Hospital Trusts) found intra-organisational barriers/enablers to staff engagement in a collaborative initiative. In one of these studies the lack of resources and unstable environment (due to organisational changes) in their own NHS hospital trust was a barrier to collaboration for some, yet for others these were the factors that motivated staff to join forces with their counterparts in other trusts.[178] In the single quantitative study, work climate – which related more to the management structure than culture - was a significant predictor of collaboration in a health-care setting.

2.6 Discussion

This review addresses a gap in the current literature as it focuses solely on intra-organisational barriers/enablers to knowledge-sharing and collaboration identified from, and measured in, a public sector population. Specifically, in knowledge-sharing it has highlighted inconsistencies in the body of relevant empirical studies in the definition and measurement of factors. The target populations also varied, ranging from service staff to upper management. This and the type of organisation may have impacted on knowledge-sharing. These issues make it difficult to determine the true barriers/enablers to knowledge-sharing in the public sector.

Except for the literature focused on nurse-clinician collaboration there was little published literature regarding intra-organisational collaboration in the public sector. This reinforces Diamond et al's point that 'in reality, intra-organisational collaboration is rarely prioritised, resourced and commended' (p289).[177] In contrast to the included literature on knowledge-sharing, most studies of intra-organisational collaboration were conducted in a health care setting. It is unclear whether intra-organisational collaboration in government and public sector is commonplace and not an issue or is deemed to have little benefit and therefore has not been the focus of research.

Although the exploration of barriers/enablers to knowledge-sharing and collaboration is not a unique or novel area, the settings and situations of those in a NIHR PPI role are. This has been a challenge in this review. None of the included studies were conducted in an organisation quite like the NIHR with its unique composition of sets of work 'units' across regions, each set with the same focus, for example Biomedical Research Centres and early phase research. In the literature exploring barriers/enablers to sharing and collaboration in a health and social care setting, the groups of interest often have a different role in the client pathway. Their goal is more likely to be integration than collaboration, to remove the kinks in that pathway. The situation is different in NIHR as those in a PPI role in the infrastructure essentially undertake the same job. They share a goal to involve patients and public to ensure research addresses a question of importance to patients, its design and conduct is sensitive to the needs of its participants (which in turn should improve recruitment rates), and the findings are disseminated more broadly than the scientific community.

Limitations

The body of literature focusing on the private sector was much larger and its exclusion could be considered a limitation. However, with regard to knowledge-sharing, the private and public sector literature reflects different organisational values. The rationale for increasing knowledge-sharing and collaboration is the same for both, namely, to make the organisation more efficient, but the end goal differs. In the public sector the ultimate aim of knowledge-sharing is to provide a better service to those who engage with the organisation. For the private sector it is competitive advantage over rival businesses. The stakes are higher in the private sector where knowledge-sharing is considered key to the survival of the organisation.

Despite the key focus on competitive advantage in the private sector, the concepts of knowledge sharing are remarkably similar to those in the public sector. Three conceptual frameworks of private sector knowledge-sharing were identified. The two earliest include three concepts: the nature of knowledge – what is knowledge, value of knowledge - motivation to share, and the opportunities/mechanisms to share.[183, 184] In one of these frameworks the three concepts were embedded within the organisational culture (including workplace subcultures).[184] A more recent framework cited the key concepts to be organisational culture, organisational structure, rewards systems, motivation, interpersonal trust, management support and information communication technology.[185] All of these were found in the public sector literature. Therefore, concepts reported as barriers/enablers in both the commercial and public sector literature informed the analysis.

In comparison to a systematic review of private sector intra-organisational knowledge-sharing[186] all but three barriers/enablers match those identified from the public sector literature. These three, categorised as individual barriers, were distrusting the source of the knowledge, a fear of sharing something confidential or fear of sharing something that was incorrect. They all relate to individuals’ concerns about the costs and consequences of drawing upon or sharing knowledge that could be inaccurate and breaching confidentiality. The authors attribute these concerns to organisations with a blame culture, where an ethos of learning from mistakes is not valued by management and employees are in ‘fear of being punished’ (p443). This fear is potentially due to the value private sector organisations place on effective knowledge-sharing giving them a competitive edge and ensuring their survival. In the public sector the existence of a blame culture and fear of reprimand was reported in only one study, conducted with local authority staff, and considered to be a barrier attributable to the organisational culture[161]. The fact that this was not found to be a barrier in the other 35 studies may be due to the different values of the private and public sector.

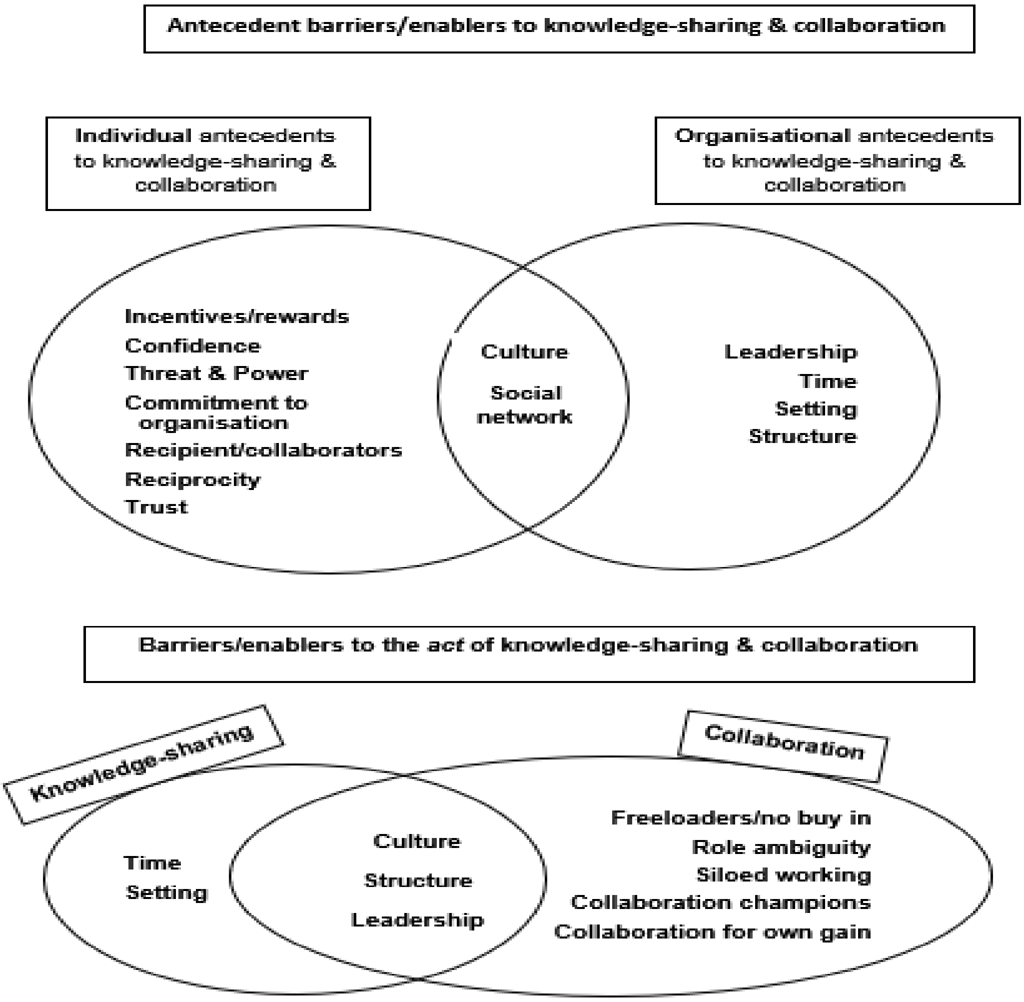
Although the concepts and the majority of barriers were the same in the private sector literature, there are two key reasons for excluding it in this review. First, there was a lack of consistency in findings in the public sector literature - due possibly to the type of organisation and the role of the individual within the organisation – and this may have been compounded with the inclusion of private sector literature with its wide range of type and size of organisations (multi-national to small and medium enterprises). Second, it would be problematic to reconcile the private sector workforce barriers/enablers with those of the public sector considering the different values and goals of the organisations. Including the barriers/enablers identified in the public sector – and acknowledging what lies behind these – in the conceptual framework makes it more applicable to the NIHR context.

Regarding the conduct of the review there were undoubtedly some trade-offs with the decision to filter quantitative studies with the framework of barriers/enablers identified in the qualitative studies. The small number of qualitative studies capturing the views of a relatively small number of public-sector workers means some barriers/enablers to knowledge-sharing may have been missed. Also, judging by the structure of the questions, one qualitative study did not adopt a truly open exploration of the barriers/enablers. Despite these issues, a strength of this review is the inclusion of only those studies where the barriers/enablers measured have been elicited from a public sector workforce.

Summary

Despite the limitations and flaws in the literature this review has been important for this project. First, it has highlighted that some barriers/enablers are contingent on others and should not always be considered in isolation. One example is whether incentives/rewards lead to knowledge-sharing can be dependent upon organisational structure. Second, it has helped to draw a distinction between the pre-conditions or antecedent barrier/enablers to knowledge-sharing and collaboration and those that impede the act of sharing and collaborating, and whether these are individual or organisational barriers. Third, most factors identified as barriers/enablers to collaboration were the same as those in knowledge-sharing. Because of the mixed findings, the review will not inform data collection but the second and third points described above have been instrumental in informing the development of the conceptual framework (Figure 2.6-1). This framework is a descriptive summary of the key concepts and at this point does not represent any relationships or connections between each one. It will be applied and used as a guide at the stage of conducting the cross-case analysis.

Figure 2.6-1 Conceptual framework of barriers/enablers to knowledge-sharing and collaboration from the literature review



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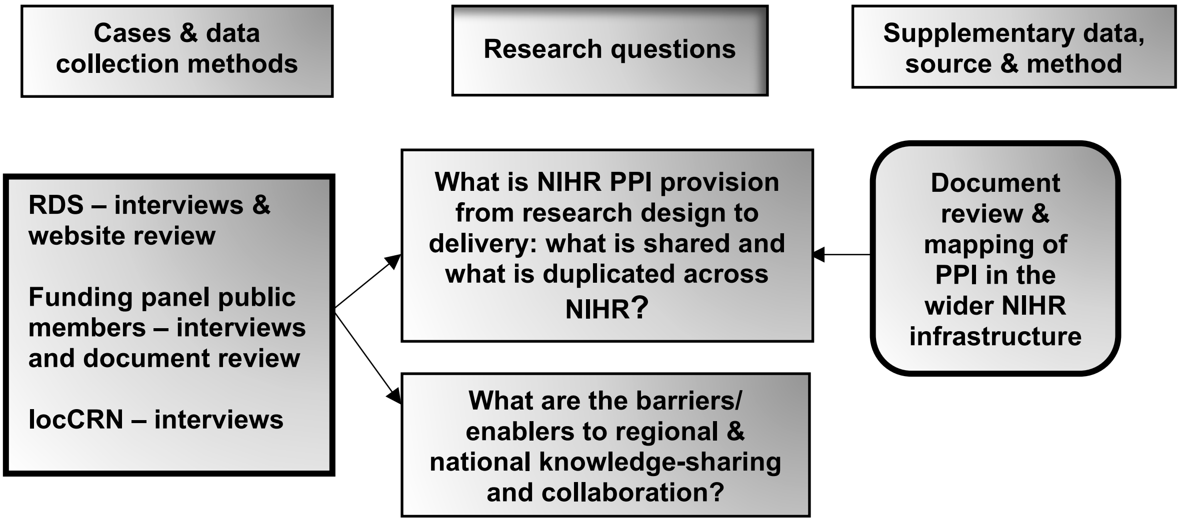
Chapter 3: Methodology & Methods

3.1 Introduction

This chapter describes, and provides a rationale for, the methods employed to address the key research questions. What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHR? What are the barriers and enablers to regional and national knowledge-sharing and collaboration?

This project employed a comparative case study design. Data were collected through interviews with NIHR staff in a PPI role within the Research Design Service (RDS) and local Clinical Research Networks (locCRN), and with NIHR funding panel public members; supplementary data were obtained from a document review and mapping exercise to identify regional sharing and collaboration with other NIHR infrastructure organisations (Figure 3.1-1)

Figure 3.1-1 – Data sources and methods to address overarching research questions



This chapter has two main components: an overview of the research approach (Section 3.2) and a critical account of the research procedures (Section 3.3). The first is a brief description of potential and selected approaches (paradigm), ontological and epistemological stances, conceptual frameworks, research designs, methods of data collection and analyses. This second provides a detailed and critical account of the research procedures, for example, sample selection, identification and recruitment of participants, and data collection and analysis. The chapter concludes with reflections on the project design and procedures and concluding remarks.

3.2 Research approach

3.2.1 Selecting a conceptual framework

Regardless of study design, empirical studies must be 'connected to the literature or concepts that support the need for the study, be related to the study's purpose statement and situate the study in terms of previous work' (p120).[187] Concepts can be presented visually or textually in a framework[188] described as 'the system of concepts, assumptions, expectations, beliefs, and theories that supports and informs your research' (p39).[189] Rocco and Plakhotnik state 'The goal of a conceptual framework is to categorize and describe concepts relevant to the study and map relationships among them' (p122).[187] Though it may evolve as the research progresses, in the initial stages it helps organise the researcher's ideas and provides a map of the research area. It also informs research conduct and from it the paradigm, or approach to the research, and the methods are decided.[190] Without a conceptual framework the study may drift and lose focus.

The terms theoretical frameworks, conceptual frameworks and models are often used interchangeably in the literature[187]; the distinction between theoretical and conceptual frameworks in particular is often vague.[191, 192] In the literature research paradigms, for example interpretivist, have been referred to as theoretical and conceptual frameworks, and the higher level general theories, such as Marxist theory, as theoretical frameworks.[193] The confusion between theoretical and conceptual frameworks is understandable in many respects as the two share a number of functions: they are the foundations for the exploration, they provide a map to guide the researcher through the study, and are instrumental in deciding upon the choice of methods.[190] They differ in that theoretical frameworks offer an explanation *for*, and conceptual frameworks an understanding *of*, a phenomenon.[191] A conceptual framework may evolve as the study progress whereas a theoretical framework remains static; the former is less developed and links abstract ideas to empirical data.[193] Imenda offers a useful definition and application of the two frameworks (p189):[194]

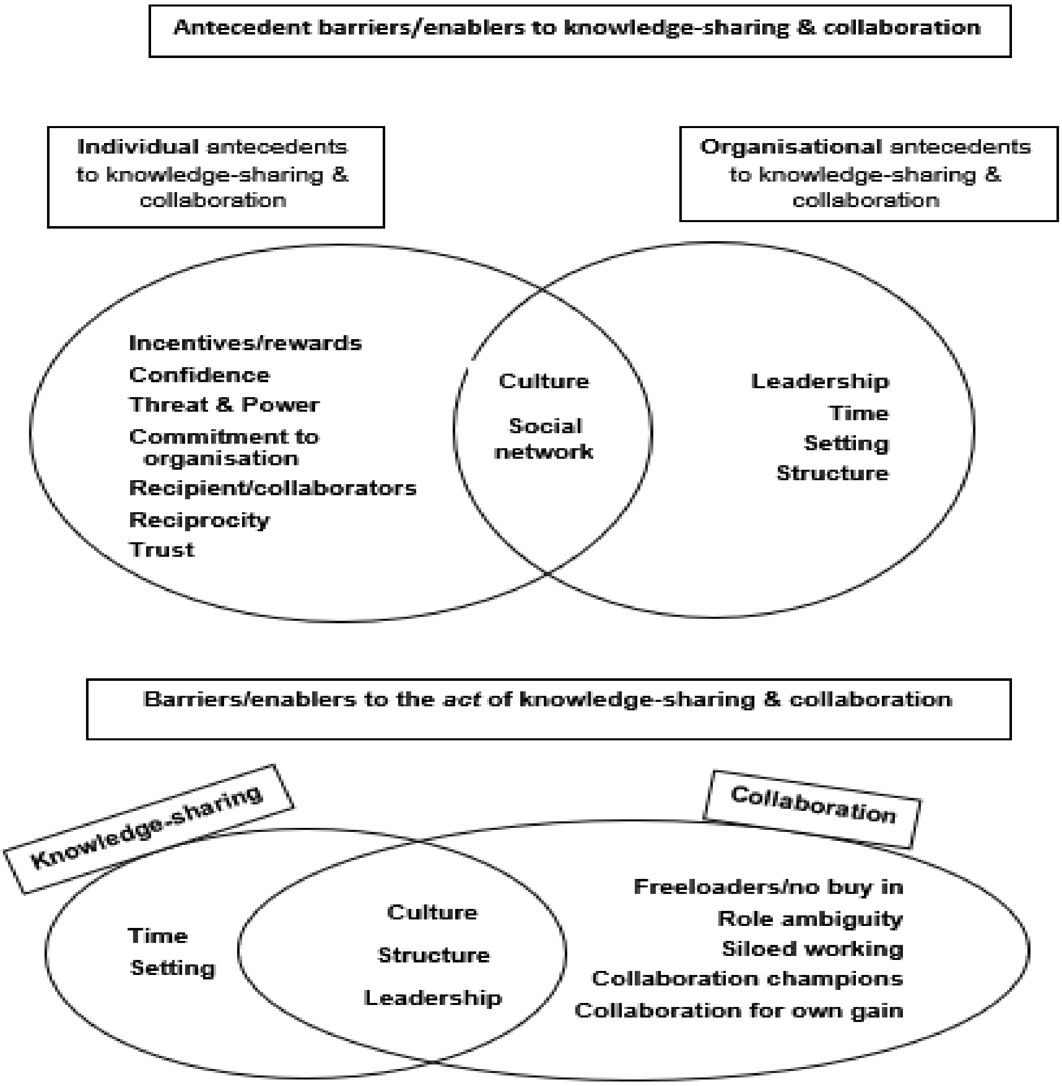
> *'A theoretical framework is the application of a theory, or a set of concepts drawn from one and the same theory, to offer an explanation of an event, or shed some light on a particular phenomenon or research problem.'*

> *'a researcher may opine that his/her research problem cannot meaningfully be researched in reference to only one theory, or concepts resident within one theory. …. In such cases, the researcher may have to "synthesize" the existing views in the literature concerning a given situation – both theoretical and from empirical findings.* (into) *a model or conceptual framework …* (to) *give a broader understanding of the phenomenon of interest'.*

Conceptual frameworks are developed from the literature – where concepts, theories and models may be identified - and the researcher's own knowledge, experience and understanding of the topic area or phenomenon.[195] Searches for established conceptual frameworks should extend to other fields of research, and it is important to review different ones. A single conceptual framework may not fully describe the phenomenon of interest and others may be required for different aspects of the problem.

A conceptual framework of public sector knowledge-sharing and collaboration determinants (Figure 3.2-1) was developed for this project from the literature review (Chapter 2). No 'ready-made' frameworks of barriers/enablers to public sector intra-organisational knowledge-sharing or collaboration were identified in the literature review, possibly due to the lack of studies conducted in this specific setting.

Figure 3.2-1 - Conceptual framework of barriers/enablers to knowledge-sharing and collaboration from the literature review

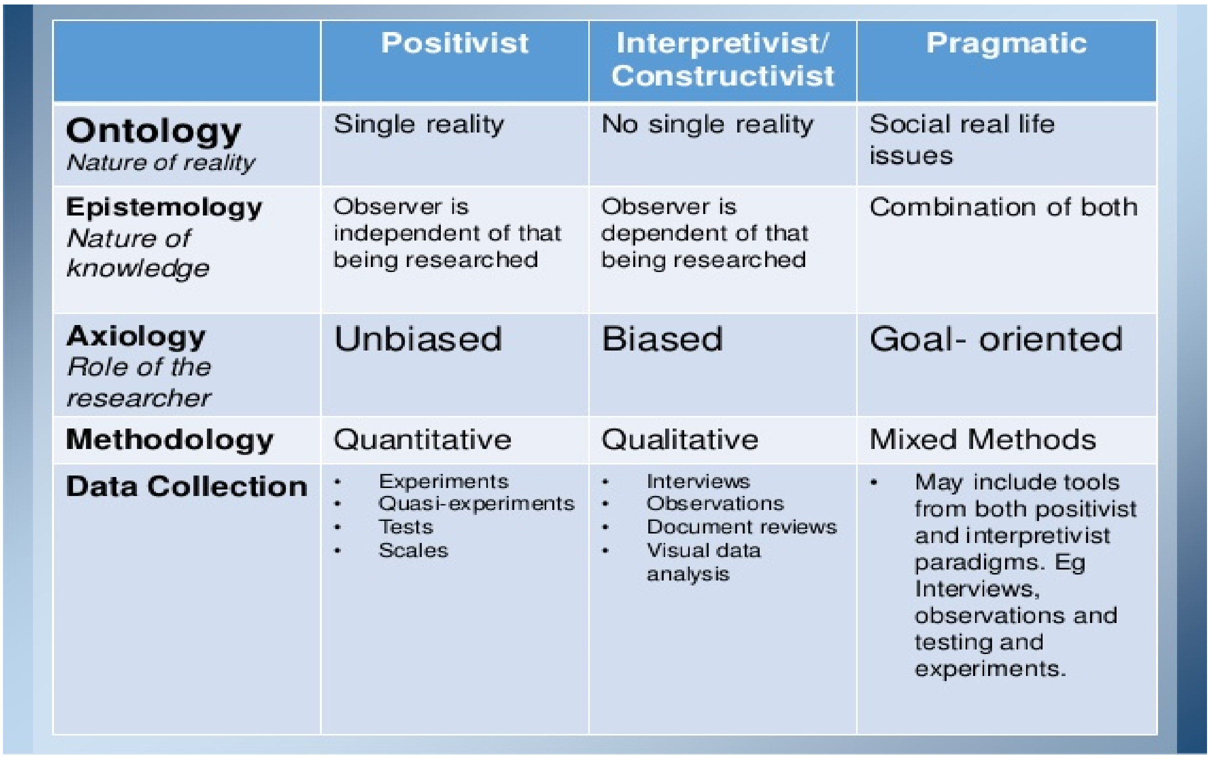


This conceptual framework was employed at the stage of data synthesis (Chapter 8) and amended in light of the findings and will be discussed further in Chapter 9.

3.2.2 Theoretical paradigm

In the social sciences, a paradigm is defined as a ‘basic belief system or worldview that guides the investigator’ (p104).[196] This ‘worldview’ informs how the researcher approaches the specific research question, what data is collected, who from and how. Paradigms have three components: ontology - ‘what constitutes the social world and how we can go about studying it’ (p35)[197]; epistemology – ‘our ideas about the nature of evidence and knowledge’ (p35)[197]; and axiology – ‘the role and impact of the researcher's values on the research process’ (p6).[198] These components guide the selection of the appropriate methodology. The three main paradigms in social sciences are positivist, interpretivist/constructionist and pragmatic (Table 3.2-1).

Table 3.2-1 - Three key paradigms in social research



	Positivist	**Interpretivist/ Constructivist**	**Pragmatic**
Ontology *Nature of reality*	Single reality	No single reality	Social real life issues
Epistemology *Nature of knowledge*	Observer is independent of that being researched	Observer is dependent of that being researched	Combination of both
Axiology *Role of the researcher*	Unbiased	Biased	Goal- oriented
Methodology	Quantitative	Qualitative	Mixed Methods
Data Collection	• Experiments • Quasi-experiments • Tests • Scales	• Interviews • Observations • Document reviews • Visual data analysis	• May include tools from both positivist and interpretivist paradigms. Eg Interviews, observations and testing and experiments.

Maliterature (2016) Research Paradigms [Powerpoint slides] Retrieved from https://www.slideshare.net/maliterature/research-paradigms-lec2

Traditionally, positivists have mirrored the methods and approaches employed in the examination of the natural world, in that of the social world.[197] The positivist ontological and epistemological standpoint is there is a single reality and the researcher, although in control of the research, remains independent of what they are researching to reduce bias in the results. This paradigm employs objective quantitative research methods to measure observable events, for example, in experiments using tests and scales.[199] An example of a positivist approach would be a clinical trial of a drug intervention for people with diabetes; objective measures of change taken from both the intervention and control (non-intervention) group such as blood glucose levels would determine the effect of the intervention. The aim is to test a hypothesis and there would be little interest in what is considered as subjective views, for example in a drug trial the subjects' views and understanding of trial processes such as randomisation or of the trial intervention other than recording any side-effects.

In an interpretivist/constructivist paradigm how people understand the world they live in is believed to be socially created.[197] The researcher is interested in the experiences and opinions of the individuals who are the focus of the research. The ultimate goal is to understand *why* and *how* something happens (or does not happen). Ontologically there is no single reality only multiple ones, and these are constructed by individuals. The epistemological assumption is that knowledge is based on the accounts of the research participants and the researcher's experience and background will impact on the findings. This approach lends itself to qualitative methods where the views and experiences of the research subjects are explored and their responses probed in depth.

The third commonly applied paradigm is pragmatism where the sole focus is the problem being explored and the questions being asked. Advocates of this approach are interested in finding a solution to a problem and change is the overarching aim. Creswell states 'pragmatism is not committed to any one system of philosophy and reality' (p10)[200] and as reality is based on individual actions it is ever-changing. The choice of data collection methods is of those most appropriate to answer the research question. As the research is driven by the questions, studies within a pragmatist paradigm often employ a variety of methods.

Of these three research paradigms, a constructivist approach with its focus on multiple realities constructed by individuals was the most appropriate in the context of this project. In contrast to a positivist paradigm, where the interest is in quantifying the responses and discovering *how many,* a constructivist paradigm aims to understand how individuals construct the concepts of sharing and collaboration and their meaning in the context of NIHR PPI provision. Pragmatism may have been an appropriate approach had there been more empirical data published about the barriers/enablers to public sector intra-organisational knowledge-sharing and collaboration. An awareness of the barriers/enablers could have moved the question to the next stage of identifying solutions and ways to instigate change; here a pragmatist paradigm would have been appropriate. The lack of data and the unique organisational structure of NIHR points to a constructivist approach which enables exploration of the issues and context.

A constructivist approach also acknowledges the impact of the researcher (axiology) on the research. My relationship to the researched was not independent and all informants (and those initially approached for access) were aware of my NIHR RDS role. Because of this shared understanding of the wider NIHR (and specifically of the RDS) the dialogue was a shared construct between myself and informants.[201]

Studies within a constructivist paradigm have been conducted across a range of settings, from educational[202], organisational[203] to health care[204] [205] and exploring researchers attitudes to PPI in research.[53] One common feature of these studies is the need to understand the attitudes and perceptions of the population of interest, their multiple realities and construction of the phenomenon that was the focus of the research. This constructivist paradigm fitted well with the research question and the need to explore the individual view.

3.2.3 Methodological paradigms

The quantitative and qualitative methodological paradigms have emerged from different philosophical traditions. Quantitative research is based in a positivist paradigm where the ontological and epistemological assumptions are that there is an objective reality, that can be known, explained, and measured empirically. Historically, a quantitative paradigm has been the choice for experimental hypothesis testing/generating studies and considered to be more ‘scientific’ than a qualitative paradigm because of the objectivity in the selected research and the aim of reducing researcher bias. Robust quantitative research aims to determine the validity, reliability, and generalisability of the results of the experiment or study.

There has been a longstanding debate about the scientific robustness of qualitative research particularly in comparison to quantitative. However, each answers very different questions. As Barbour states

> *‘Qualitative methods cannot answer questions such as ‘How many?; ‘What are the causes?’ What is the strength of the relationship between variables?’ yet can make visible and unpick the mechanisms which link particular variables, by looking at the explanations, or accounts provided by those involved.’*
> (p13).[197]

For research questions where the aim is to determine cause and effect a quantitative paradigm would be the most appropriate means of inquiry. In quantitative research the focus is on hypothesis-testing with a strict adherence to the original protocol of processes, methods and analysis. It employs objective replicable measures, such as blood tests or questionnaires, and researcher bias is reduced to a minimum. Unlike qualitative research, the findings from quantitative research methods are intended to be generalizable to the larger population. To ensure generalisability of the findings careful thought is given to the sample recruited to the study. The goal is to draw a random sample to ensure those who participate are representative of the population of interest.[206] The sample is usually a probability or random sample of the population of interest; the size determined by the variability in the population on the measures of interest and the type of analysis proposed.

In this project a quantitative methodological paradigm was not appropriate; too little is known about sharing and collaboration in this population to measure the concepts using the scales identified in the literature review (Chapter 2) in a survey instrument. The exploratory nature of the project, the need to collect descriptive detailed data on PPI provision, and the known heterogeneity of the population of interest (there are NIHR staff with a responsibility for PPI at different levels of seniority within the organisation) precluded the use of quantitative measures.

A qualitative methodological paradigm was the most appropriate to answer research questions focused on exploring the perspectives of those in an NIHR PPI role. This paradigm stems from an interpretivist philosophical tradition and the assumption and beliefs ontologically are that reality is constructed through social interactions and experiences[207]; and epistemologically, that the self and what we know are intrinsically connected, 'who we are and how we understand the world is a central part of how we understand ourselves, others and the world' (p1).[208] A qualitative approach is the natural choice when the research question seeks to understand in depth the experiences, perspectives and behaviour of the research subject.[192]

Qualitative research can be iterative 'whereby the research design 'tools' and even the research question can evolve as the project unfolds. This allows for the testing of emergent 'hypotheses' or explanations.'(p27).[197] In addition, the measures to check the validity of data in quantitative research are not required in qualitative research that 'recasts inconsistency as a resource or intriguing analytic puzzle rather than a problem of disconfirmation' (p21).[197]

Within a qualitative methodology there are different forms of sampling: quota sampling where a particular number are recruited to fulfil pre-set criteria[209]; snowball sampling where participants suggest other potential participants[210]; and, the method employed in this project, purposive sampling where participant selection is guided by the research question. Within this method there are several different, though all criterion-based, types of sampling[211, 212] and as the individuals of interest in this project all had a PPI remit in their NIHR work role homogenous sampling was used.

3.2.4 Research designs in a qualitative methodological paradigm

Green and Thorogood define research design as 'the logic of the study: the what, how and why of data production' (p43).[213] The choice of study design is guided by which is the most appropriate to answer the research question(s). The research designs most often employed in a qualitative methodological paradigm are observational, action research and case study.

Observation

Qualitative observational designs are appropriate when the researcher wishes to 'describe and understand what is going on in a particular setting' (p45).[213] They provide an insight into how people behave in an everyday 'normal' setting and how they interact with each other.[197] Non-observational methods, such as interviews, can report what people *say* they do, but without confirmation from other data remain the subjective accounts of the individuals. Observations can be participant, where the researcher is an active part of a group whilst they observe what is happening, or non-participant where they merely observe without any involvement and their presence as a researcher can be covert or overt.[192] The advantages of a covert approach is the opportunity to observe a group behaving naturally who are unaware they are the focus of research.[214] There are potential ethical issues of secretly observing a group for research purposes, yet there is a strong argument that this is acceptable as long as the privacy of those involved is protected.[215] For non-participant observations the disadvantages include difficulty gaining access to the setting, the limited amount of time the researcher spends in the setting, and the time required for the observed to become accustomed to the presence of the observer or video equipment.[216]

In the context of this project, a purely observational design would have provided extremely detailed data on the phenomena of interest but limited the breadth of NIHR PPI staff and NIHRio involved.

Action research

In action research - sometimes called ‘participatory research’ - the researcher and the research subjects work together to study and bring about change which has been agreed by both.[192] It is described as ‘one of the few research approaches that embraces principles of participation, reflection, empowerment and emancipation of people and groups interested in improving their social situation or condition’ (p195-6).[217] It involves an iterative process of multiple cycles of inquiry, action and reflection.[218] The topics are frequently political in nature and there is a need for flexibility because the ever changing landscape may impact on the study.[197] Mixed or multiple methods are often chosen. Barbour describes two models: community development often with a ‘bottom up approach’ and professional research and development with a ‘top down’ approach’ (p169/70).[197] The challenges of this design include the generalisation of findings to a different setting (particularly if the focus of the research has been on a local issue) and the lack of consideration of how studies have contributed to theory.[192] At a pragmatic level, the multiple cycles of inquiry described above can become complicated if some of those involved are ready to move to the next stage and others are not.[197]

Regarding an action research approach, although this project is founded on the exploration of a problem – duplication of NIHR activities – this is anecdotal. With this approach exploratory research would be needed to identify whether this was in reality a problem and if so in which part(s) of the NIHR infrastructure. Securing the involvement and participation of stakeholders (NIHR PPI staff) in action research could be problematic.

Case study

An instrumental comparative case study design was selected for this project. Case studies have been described as the 'intensive' or 'in-depth' description and investigation of a phenomenon in its natural setting.[219] This design has a long history in social sciences research[216], but interest has waxed and waned over the years until a revival in the 1980's[220] primarily through the work of Robert Yin, Robert Stake and Sharan B. Merriam.[221] It is appropriate when the aim is to study a phenomenon in a real-life context using a range of data sources, such as documents, interviews and observations. A key characteristic of case study research is the identification of the case 'that will be described and analysed' (p97).[216] The 'case' could be 'an individual, a company, a decision process, or an event' (p97).[216] Cases must be bounded systems, which Merriam describes as 'a single entity, a unit around which there are boundaries. I can "fence in" what I am going to study.' (p40).[222] Stake outlines two types of cases based on the intention of the research: an intrinsic case where the *case* is of specific interest; and an instrumental case where the intention is to explore a phenomenon.[223] Within the instrumental case study type, the focus can be a single bounded case or multiple cases (a collective or multiple case study). Creswell states 'often the inquirer purposefully selects multiple cases to show different perspectives on the issue' (p99).[216] Some drawbacks of a case study design are: managing the large volume of data generated and the need for clear strategies for the analysis and integration of the data; losing the focus of the research; and presenting the findings of multiple case studies in a coherent manner.[219]

Other studies exploring knowledge sharing[224-226] and collaboration[227-229] in an organisational context, have used a case study research design. This design does not advocate a specific method of data collection and acknowledges strength in drawing upon data from different sources.[219] Similarly a range of analytic methods can be employed depending on the type of case study.[230] Sections 1.6 and 1.7 outline the chosen methods of data collection and analysis.

3.2.5 Qualitative data collection methods

This project employed two methods of data collection as part of a comparative case study design: interviews and document review. The alternative methods of focus groups and observations are first discussed.

Focus Groups

When the researcher is interested in the interaction between the group attendees and the direction the discussion takes focus groups are appropriate.[231] They 'allow the researcher not just to observe who says what, but also who speaks most, which kinds of staff dominate, and whose comments are taken seriously.' (p133).[213] Focus groups are less likely to be used when the aim is to explore individuals' views in-depth or when the topic is sensitive (though this can sometimes work well in groups) and attendees may feel inhibited to participate. In comparison to interviews, focus groups are often considered as an efficient method to obtain the views of several people in one session. However, to produce high quality data there are a number of considerations, such as group size and composition, a venue where distractions, interruptions and noise will be kept at a minimum, and the need for skilled facilitators/moderators to ensure they run well and produce good data.[231] Facilitators/moderators must deal with attendees who are quiet and contribute little and those who dominate the discussion.[216] Their limitations include: difficulties accessing marginal views in a group setting; ensuring attendees are representative of the range of stakeholders of interest; accessing in-depth individual narratives.[213]

In this project it may have been interesting to capture PPI staff's discussions about shared and diverse experiences through focus groups. However, it would have inhibited participants from talking about the barriers experienced particularly as others in the group may be the very people they are, or should be, collaborating and sharing with.

Observation

Observation with its roots in anthropology, is a method of collecting data on the verbal interactions between those observed and how they behave, in a naturalistic setting. It is a key element of ethnography, often along with interviews or focus groups. Observations provide an opportunity to 'see how work or social practices are enacted on a daily basis' and can 'illuminate the discrepancies between intent and outcome' (p19).[197] Whether participant or non-participant, they can generate a huge amount of data which may impact on the time taken to analyse. The method requires a particular skill set and training and, if not video-recorded, an ability to retain what has been observed to later write up the field notes. Overt research encounters neither of these problems but the disadvantage is the observed may behave differently knowing they are being researched.[232] Where it is inappropriate or difficult for the researcher to be present to observe the phenomenon in 'real time', video- or recording equipment is sometimes used. One advantage is that video- and audio-recording equipment is now small, discreet, and less obtrusive than a person. However, to capture non-verbal cues in real-time is with video would require a few cameras in situ.

Observational data on the workings and dynamics of regional PPI groups in this project would have been interesting. However, to collect sufficient and meaningful data, several observations of each group would be required and considering some met infrequently this could result in a very lengthy data collection period. Observations would have limited the breadth of NIHR PPI staff involved, perhaps limiting the NIHRio to one and selecting one or two regions.

Interviews

Interviews are possibly the most often used method in qualitative research. An interview has been described as a situation where ‘knowledge is constructed in the interaction between the interviewer and the interviewee’ (p163).[216] Through this interaction the interviewer and interviewee ‘produce language data about beliefs, behaviour, ways of classifying the world’ (p103).[213]

Although the focus of the inquiry guides which questions are asked, qualitative interviews are characterised by the use of open questions and for the interviewer to probe and explore the responses as necessary.[197, 213] There are three types of qualitative interview: *semi-structured* - where the questions are based on topics the researcher wishes to cover; *in-depth* – where there is greater scope for the interviewee to raise issues of personal importance within the broader topic area; *narrative* – where the interviewer encourages the interviewee to tell their own story within the topic of interest.[213] A more recent mode of data collection, and alternative to those described below, is the use of instant text messaging or on-line fora where the talk between the interviewer and interview is in writing.[216] These are considered beneficial when participants need more time to reflect on their responses and the research question requires the collection of longitudinal data.

Interviews can be conducted face-to-face or by telephone. In comparison to face-to-face data collection, telephone interviews are often more appropriate with sensitive topics and hard to reach populations who may be reluctant to meet face-to-face; they address issues of interviewer safety, time and travel costs.[233] Some report it difficult to develop rapport in telephone interviews, the inability to see the non-verbal cues could impact on meaning, they can result in increased interviewee fatigue and are often typically shorter.[234] A key issue is whether the data collected by telephone is inferior or different to what is collected face-to-face. A comparison of data collected face to face and by telephone reported no difference in data quality.[233] The authors conclude when the research has a ‘more narrow focus and immersion in the environment is not necessary’ (p116) telephone interviews are comparable to face-to-face. The use of a platform such as Skype to conduct virtual 'face-to-face' interviews may be considered equivalent to those in-person. However, a study comparing in-person, telephone and Skype found the former to be superior in the richness of the data produced.[235]

A topic or interview guide is typically used with 5-7 open questions[236] and probes to explore a topic in greater depth. Issues elicited in interviews can be added to the guide to explore in subsequent ones. Careful attention should be paid to the development of the topic guide and pilot testing it before use.[237, 238]

The most widely cited shortcoming of interviews is that the data is individuals' accounts of what they *say* rather than what they *do,* for example accounts of frequency of hand washing may not truly reflect the actual number.[213] Green & Thorogood state 'Interview data are valid, so long as the interview is treated as a contextual account, not as a proxy representation of some other reality' (p104).[213] A second shortcoming is interviews do not 'produce information about how people interact or behave in contexts other than interviews' (p106).[213]

In this project, interviews enabled the collection of descriptive data on PPI provision, resources and expertise from the case study informants to build a picture of what *could* be shared with other parts of the infrastructure. Interviews enabled a frank open discussion about the role of PPI and the barriers and enablers to knowledge-sharing and collaboration across the NIHR infrastructure and beyond. Telephone interviews permitted the inclusion of staff from across England and flexibility in both the timings of the interviews and rescheduling if informants had conflicting priorities.

Document review

Documents in the form of diaries, letters, newspaper/on-line articles, reports and records can be a rich source of data. Prior draws a distinction between documents used as a resource (the interest is in the content of the document and, or, how it is used as a resource by others) and as a topic (how the content was developed and, or, impact of the document on the group of interest).[239] Often used as part of mixed methods studies, documents can provide contextual information to situate or complement data collected through other means.[197] In some studies this secondary resource is the only data collected, or that is available, for example in historical research. How something is documented or presented may be the focus of the research question, for example Seale compared how cancer experiences were represented in prostate and breast cancer websites.[240] The advantages of a document review are: efficiency and cost-effectiveness; availability of the data; the data is stable and not affected by the researcher or process of collection; data can be collected from across time with detailed information (names and references).[241] The disadvantages are: a lack of detail within the documents means they may not fully answer the research question; access to documents may be difficult and if the analysis is based on incomplete data this can introduce bias.[241]

In this project the resource for the document review was the content of NIHR PPI reports. The rationale was to supplement the interview data and help build a picture of PPI provision, collaboration and sharing in the other facets of NIHR.

3.2.6 Analysing qualitative data

Qualitative analysis can be inductive, deductive or a combination of both. An inductive approach has been described as 'a "bottom-up" approach to knowing, in which the researcher uses particular observations to build an abstraction or to describe a picture of the phenomenon being studied' (p5).[242] Although this approach begins without a theory, a theory (or theories) may evolve through the analysis process. In contrast, a deductive approach could be considered as the reverse of an inductive one as it begins with a theory or hypothesis which is then tested against the data collected. Green argues no study can be purely inductive or deductive: in the former this would assume the researcher is a blank slate and does not draw on prior theories or assumptions in their interpretation of the data; in the latter, the selection of the theory or hypothesis to test involves an inductive process.[192] A combined deductive-inductive approach is often used, particularly in the development of data codes at the analysis stage. For example, the data is organised into higher level codes/themes using a pre-determined framework often based on the topic guide. This is followed by an inductive approach to develop sub- codes or themes, or those that do not fit in the higher-level framework. This process of organising the data is employed in most qualitative research approaches.[243, 244]

To move beyond the descriptive level the subsequent steps may differ depending on the research question. Four of these are described here beginning with Framework analysis followed by narrative analysis and grounded theory before concluding with content analysis which was the chosen method for the case study interview data.

Framework analysis

Framework analysis was developed in the context of policy research.[245] This is traditionally a deductive approach as it is 'shaped by existing ideas and is less focused on producing a new theory' (p2425).[246] It involves the development of a coding scheme (as described above) which is then applied to the full dataset (indexing). Two subsequent stages are 'charting' and 'mapping and interpretation'. Charting involves summarising each piece of coded data and arranging either by theme or by case. This facilitates the comparison of codes, across and within the cases, and the relationship between them. The final mapping and interpretation stage is often the presentation of the data diagrammatically to help further explore the relationships between the concepts identified from the data. As well as providing a straightforward and transparent analysis process[247], it is 'designed so that it can be viewed and assessed by people other than the primary analyst' (p116).[248] Critiques of this method are its lack of theoretical underpinning[249] and the use of charts may tempt novice qualitative researchers to quantify the data.[250]

Framework Analysis was ruled out in this project for two reasons. First the research question demanded an inductive approach and there was no a priori framework. Second because the PPI provision data was expected to be descriptive, undertaking the Framework process as described above for this data would have been labour-intensive and unnecessary.

Grounded theory

Grounded theory has been described as ‘an iterative process by which the analyst becomes more and more “grounded” in the data and develops increasingly richer concepts and models of how the phenomenon being studied really works’ (p783).[251] Developed in 1967 by Glaser and Strauss who wanted to demonstrate that theory could be developed from qualitative data and as the theory was grounded in the data was more relevant to the situation or phenomenon being researched.[252] It is more than a process of analysis and extends to the sampling strategy where new data is collected to address gaps in theoretical categories or questions arising from the data. The analysis includes coding (codes are conceptual labels) at the initial, intermediate and advanced stages[253], memoing of analytical ideas from the researchers’ notes during data collection and throughout the coding process[192], and constant comparison - the process of comparing every piece of data, code and category, within and across each to aid the interpretation of data. Constant comparison has evolved as a method in its own right and is used outside of grounded theory.[254] The generation of new theory and the ability ‘to look at phenomena with new eyes and from new perspectives without restriction within already existing hypotheses’ (p16) is a key strength.[255] However, the many derivations of this approach that have emerged since its inception[256] can cause confusion particularly for the novice researcher. Theoretical sampling also makes it difficult at the outset to determine study duration.[255]

In this project a grounded theory approach was precluded as there was never an intention to generate theory. Additionally, the theoretical sampling would have been problematic with the NIHR PPI staff of interest.

Narrative analysis

With a narrative inquiry, the structure of the questions used in data collection differs to others. As the emphasis is on the individual’s story, the interviewer begins with an open question to elicit a detailed account of a particular event and does not follow the usual question and answer format of other qualitative approaches. The aim of the analysis is to determine ‘how respondents impose order on the flow of experience in their lives and thus make sense of events and actions in which they have participated’ (p339).[257] The analysis process will depend on the specific interest of the researcher: this could be *what happened, how* the story is told or constructed, or what the narrative *tells us* about a particular phenomenon. For example, for those interested in the *what,* these processes have included phenomenological analysis or a form of grounded theory, and those interested in the *how* have drawn upon conversational analysis.[258, 259] Disadvantages of narrative inquiry are the vast amount of data it can generate and, conversely, the problems encountered if the individual is not forthcoming in telling their story.

As highlighted above, narrative analysis involves the exploration of a very personal and key event for an individual. This was not suitable considering the workplace focus and research questions to be answered by this project.

Qualitative content analysis

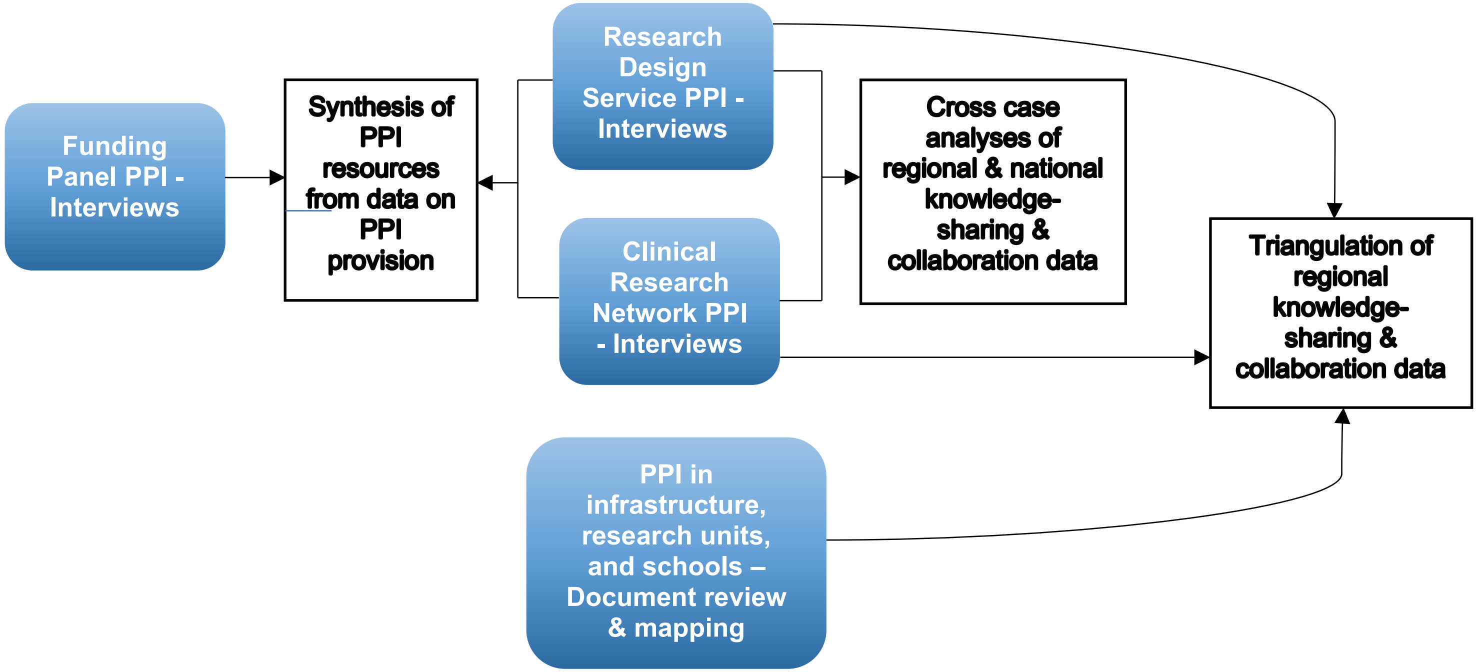
The most appropriate method of analysis for this project was qualitative content analysis. The origins of content analysis lie in the quantitative research tradition, specifically in mass media communication research to identify, describe and quantify the manifest content (the surface characteristics of text).[260] This method was criticised by those who believed meaning is more complex, and the frequency with which something is mentioned does not always equate to its importance, and led to the development of a ‘non-frequency’ or qualitative content analysis (QCA).[261] QCA is a method of systematically coding and eliciting themes and patterns within qualitative data.[262] Qualitative and quantitative content analysis share many similarities, but the former also focuses on 'latent and more context-dependent meaning' (p173).[260] The process of analysis involves building a coding frame[263] similar to the description at the beginning of this section. It is the latent content analysis, described as 'an interpretive level in which the researcher seeks to find the underlying meaning of the text: what the text is talking about' (p10)[264], that takes QCA beyond the descriptive or manifest level of analysis. Strengths of QCA are its flexibility: researchers can take a conventional (inductive), directed (deductive), abductive (moving between inductive and deductive)[265] or summative (quantifying)[262] approach. The limitations, particularly in comparison to grounded theory and phenomenological analysis, are the inability to develop theory or to shed light on the lived experience of a phenomenon, primarily due to the sampling and analysis processes.[262]

For this project, QCA provided the scope to explore manifest as well as latent content of the interview data. This fitted well with the descriptive (manifest) elements of this project, for example, PPI provision in the three NIHR cases of interest, and the need to delve deeper to explore why this population do, or do not, share and collaborate (latent). An inductive approach was employed, drawing the codes, categories and themes from the data. In the next section I provide a detailed and critical account of the conduct of the research.

3.3 Comparative case study of NIHR PPI staff knowledge-sharing and collaboration

A constructivist paradigm was selected, with its focus on multiple realities constructed by individuals. A qualitative methodological paradigm was the most appropriate to answer research questions focused on the perspectives of those in an NIHR PPI role. A comparative case study design enabled the exploration of sharing and collaboration in a real-life context. Data were collected through telephone interviews and document review. Figure 3.3-1 illustrates the data sources, methods and how the links between data sets in the synthesis and analysis stage. Newcastle University Ethics Committee approval (00774/2014) was obtained for this project (Appendix G).

Figure 3.3-1 - Data sources, methods and links



Author positionality

From a constructivist perspective there is not one, but many realities and the researcher may impact on the subjects of the research, the data collected and the interpretations of the findings. Therefore, the findings presented in this thesis are only one possible interpretation of the barriers/enablers to knowledge-sharing and collaboration, from the standpoint of an RDS senior research methodologist/advisor. Although I am an experienced researcher and have continued to be research active alongside the RDS role, this has been in the fields of clinical and health services research. NIHR PPI and workplace knowledge-sharing and collaboration was a novel topic of research for me. Regarding my personal experience of the topic, I was familiar with PPI in the RDS context in one region and had some understanding of NIHR funding panel public contributors' input through observations of meetings. RDS clients had often shared correspondence from NIHR funding panels including feedback about the PPI in their applications. When acting as a reviewer for NIHR on project final reports I had read lay reviews. All informants were aware of my role and sharing my own experience with the RDS (when appropriate) enabled me to build up a certain level of rapport in the interviews. This was particularly so with the locCRN interviews and resulted in some extremely frank disclosures about PPI, sharing and collaboration. It is possible the RDS informants may have considered me as someone who would judge their work practice rather as 'one of their own', resulting in more guarded responses. Despite this, I believe working for the RDS was beneficial, particularly because the shared understanding of NIHR, between myself and the informants, facilitated discussion and allowed the key issues of sharing and collaboration to be a key focus. The topic guide was broad, and this emphasis on an open exploration of the topic helped to reduce any bias in questioning. My own experience in the RDS may have influenced my interpretation of the role of RDS PPI advisors as I had doubts about the feasibility and utility of a move to other methodologist advisors advising clients on PPI. However, I do not believe my experience influenced the interpretation of the data beyond this single point or for the public contributor and locCRN data.

Patient and public involvement

In the early stages of the research, I discussed my ideas for the project with an ex-RDS/CRN PPI advisor. Although they had been in a salaried role their background was different to the individuals I interviewed in the study. They previously had a patient advocacy role and personal experience as an informal carer, and no training or qualification as a researcher. Despite their past role within the RDS and CRN I considered this person to be more ‘lay’ and grounded in PPI than others in my sphere. This person was available to comment on my topic guides but unfortunately not beyond that point.

The NIHR Evaluation, Trials and Studies Co-ordinating Centre and Central Commissioning Facility funding programmes connected me with public contributors regarding data collection for the case study. I explored with those who did not want to be interviewed whether they would be involved in the project for its duration. Understandably the individuals wanted to be reimbursed for their time and unfortunately, as this PhD project was not funded by a fellowship, I did not have the funds to do so. Although not ideal I have discussed my research, particularly the findings and my thoughts on their interpretation, informally with university colleagues who have an interest in PPI and NIHR public contributors I have worked with in other contexts. These individuals have been a useful sounding board.

3.3.1 Case selection

As the focus of this project was NIHR PPI in applied research, in particular clinical trials, I selected three bounded PPI groups - the RDS, the NIHR funding panels, and the locCRN - as cases (Table 3.3-1). The unit of analysis was those with a PPI role within each case. Multiple cases were selected to enable a comparison of experiences and perspectives on the phenomenon from the different parts of the NIHR infrastructure (Table 3.3-2).

Table 3.3-1 – Descriptions of the three selected case studies

NIHR Organisation/group	Number across England	Place in research pathway	Role of organisation/group	Informants and role	Timing of data collection
Research Design Service	10	Development of research question into a project	Advice and support in the development of research funding applications	PPI Leads (advise on involving patients/public in study design)	May-Nov 2017
Funding panels for: • Health Technology Assessment Programme • Efficacy & Mechanistic Evaluation • Research for Patient Benefit • Programme Grants for Applied Research	16 panels	Funding stage	Review research project funding applications. Consider importance of research question to NHS and patients, scientific and methodological quality, feasibility and cost. Decisions on whether or not to fund research applications	Lay funding panel members (review applications from a patient perspective, review level of PPI in development of application and duration of project).	Dec 2016 – May 2017
Local Clinical Research Networks	15	Delivery – from study set up to end of recruitment	Support the delivery of funded eligible* research studies. Monitor recruitment up to end of recruitment period.	PPI Leads/officers (advise on PPI in the delivery of research studies)	Stage 1 2015 Stage 2 2017

*Those on the CRN Portfolio – i.e. all NIHR funded studies, all commercial studies

Table 3.3-2– Comparison of cases and their contribution to NIHR

Case	Symmetry (across cases)	Differences (across cases)	Attributes	Contribution to NIHR	Setting	Stage of research process	Professional or contributor
RDS	Advise on PPI in conduct of study	**Advise** on PPI in the development of research ideas, in the design of studies, development of proposals, and PPI for the duration of studies (conduct and dissemination)	Advisory	Producing funding applications with meaningful PPI	Regional	• Generating/refining research question • Design	Professional (with input from public contributor/s)
Funding panel public contributors	Review PPI in conduct of study	**Review** plans for PPI in funding applications and feasibility from a patient perspective	Review and advisory	Contribute to panel decision making	National	• Funding	Public contributor
CRN	Support PPI in conduct of study	**Support** funded CRN portfolio projects with PPI (particularly if failing to recruit study participants)	Support function	Delivery of studies to time and target	Regional	• Delivery	Professional (with input from public contributor/s)

A purposive sample[266] was appropriate as the population of interest were those fulfilling a specific role or responsibility for PPI within NIHR. The intention was to recruit an individual in a PPI role from nine[4] RDSs, all 15 local CRNs, and at least one public contributor from four of the NIHR funding panels.

Identification and recruitment of informants

Two PPI leads identified from searches of the nine RDS websites were emailed about the project. For the remainder, the email was sent to each RDS generic 'team' email address (five) or, when available, the RDS director (two). The two directors and four of the five teams forwarded my email to the relevant person. A second email was sent to the RDS team who had not responded; when there was no response I identified and contacted their director. This director chased this up but there was no response.

As none of the 15 locCRN websites provided the details of the PPI Leads, the Chief Operations Officers (COOs) were contacted by email. The one exception was the locCRN PPI Lead in my own region who I contacted directly. The email asked for the name of the PPI lead or the most appropriate person to approach to interview. In the main, this worked well, though did result in some COOs volunteering to be interviewed. This was problematic in only one case where the informant was guarded in their answers and continually suggested the 'national' team, i.e. those at the CRNCC, more appropriate to provide the information, when in fact the local perspective was of interest. Finally, as this informant was unable to provide the information required, they suggested I speak to their PPI lead; ironically this was the person I had originally sought to interview.

As the funding panel public member emails were not available on the website the chairpersons were contacted. The chairs of the HTA, EME and RfPB - outside of the

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[4] At the time of data collection I worked for RDS North East and considered it unnecessary to interview the PPI lead as I was cognisant of the PPI structure and provision.

Yorkshire and North East region - funding programmes were asked if they would forward my request to their public contributors. For the PGfAR funding panels the PPI team at the Central Commissioning Facility (CCF) contacted their public contributors on my behalf who then responded to me directly if they wished to participate.

The email (Appendix H) explained the purpose of the study and offered a tele-meeting to discuss the study prior to committing to an interview. If there was no response to my email within two weeks the original email was resent. No one requested a tele-meeting – though some did ask detailed questions about the study at the time of the interview - and were happy to proceed and arrange a date and time for the interview.

Data collection tools and time-points

Interview topic guides were designed for each of the three groups (Appendix I). Within a constructivist paradigm the questions should not be too prescriptive and enable the informants to ‘construct the meaning of a situation’ (p8).[200] Similar draft topic guides were developed for the RDS and locCRN interviews to facilitate comparison. These were pilot tested with someone who had previously had a locCRN and RDS PPI role. Piloting with the target population would have eroded the pool of available informants (some RDS/locCRN had only one PPI staff member) and involving individuals in both development work and as study ‘subjects’ impacts upon the spontaneity of responses in the interviews.

The lay funding panel member topic guide focused more on the individual and began with questions to build up a picture of their ‘PPI’ background and experience before moving to more specific questions about training (support, resources and schemes offered by the funding stream) for their role, and how they operationalise PPI in the review of funding applications. Colleagues who were NIHR funding panel members (not lay) reviewed the guide and suggested to also explore the buddy/mentor system offered by some funding streams.

The guides evolved over the course of data collection when points were raised considered worth exploring in subsequent ones. The questions worked well, and I was often surprised by how forthright some informants were.

The majority of locCRN interviews were conducted in October/November 2015 and two in April 2016 because the nominated PPI staff were unavailable. At the time of these interviews the local CRN staff had only recently come to the end of a period where the network had transitioned from 104 networks to 15. There was a degree of uncertainty and turmoil for some, and PPI provision was under review. Because of this the informants were asked if they could be contacted 12-18 months later to arrange a second interview. A second round of interviews was conducted February – April 2017. If Stage 1 informants had moved to other posts their replacement or another person was interviewed where possible. This was the only group where a second interview was carried out. At the second locCRN interviews, topic guides (Appendix J) were tailored to revisit points raised in the previous interview and how PPI initiatives had progressed. Interviews with funding panel public contributors were conducted between December 2016 and April 2017 and with the RDS between May and November 2017.

Consent was obtained for the recording and transcription of interviews. Informants were assured that transcribed data would be anonymised, and they would not be identifiable in any reports or journal articles. If I had any doubts, we agreed I would send the draft to the relevant informants for comment before submission.

Interview duration ranged 11.18 to 58.36 minutes and an average of 38 minutes across the three groups. This average interview length for semi-structured interviews is not unusual[267] particularly with professional groups when the topic is not particularly sensitive. Interviews were transcribed verbatim and the transcripts uploaded to NVivo which was used as a management tool.[133]

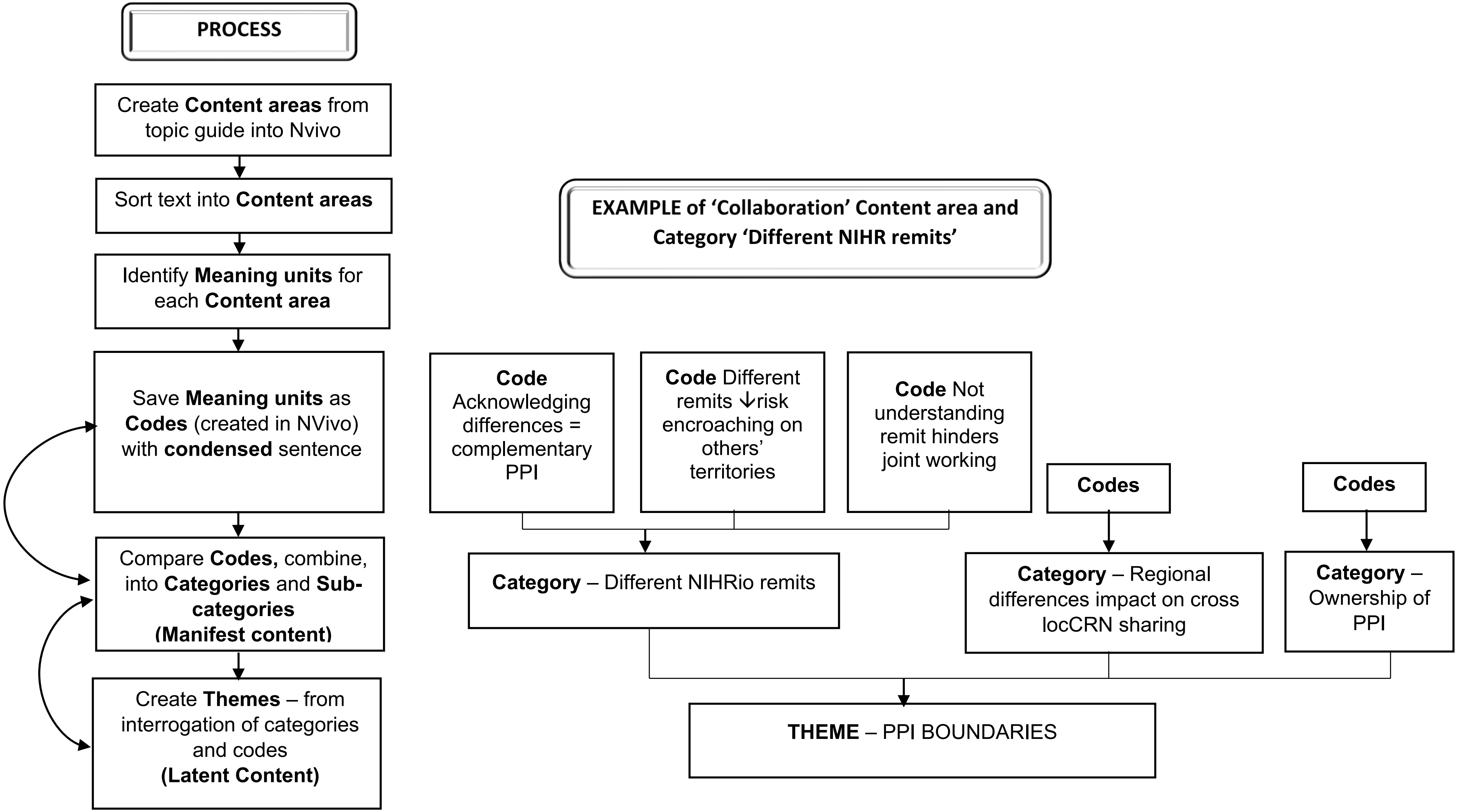
Within case analysis

The QCA process is described and outlined in Figure 3.3-2 with an example from the locCRN case study data. The interview data were sorted into the content areas from the topic guide and a framework was created in NVivo[133] with the content areas as nodes. A process of data familiarisation was undertaken by reading through the interview transcripts and listening to the sound-files. During this process text relevant to content areas was saved into the respective node and meaning units (sentences or paragraphs) were identified. The meaning units were given a code (a label) and saved as child nodes (a sub-node) in NVivo. Condensed sentences were attached as a descriptor and reminder of the core meaning. These codes were then compared and combined, where necessary, into categories and sub-categories. This is the point at which the manifest content is derived. To explore the latent content, the categories and codes were interrogated, compared and contrasted to identify themes. Themes have been described as ‘a thread of an underlying meaning through, condensed meaning units, codes or categories, on an interpretative level’ (p107).[268] The process entails stepping back and asking ‘What is really going on? What is the implicit message?’.

Figure 3.3-2 provides an example of the codes abstracted into the category ‘Different NIHRio remits’, and the abstraction of that and two other categories into the theme ‘PPI boundaries’. As indicated in the figure the researcher goes back and forth refining and re-evaluating the meaning units, codes and categories.

In this project a model of inductive thematic saturation was adopted, where analysis was discontinued when no new meaning units or codes were elicited from the data.[269]

Figure 3.3-2 - Qualitative content analysis process with example from locCRM case data



Cross-case analysis

In a multiple case study design the suggested process is to conduct a *within* case analysis and then a *cross* case analysis.[216] Cross-case analysis has been described as ‘the analysis and synthesis of the similarities, differences and patterns across two or more cases that share a common focus or goal’ (p1).[270] However, it is important to preserve the essence of the individual cases from the within-case analysis.[271] The aim was to build a picture of the barriers and enablers across cases in two analyses: the first for regional and the second for national knowledge-sharing and collaboration. The cross-case analyses involved five steps as described below.

Steps 1 and 2 - Sorting and synthesis coding

A protocol devised to explore convergence, complementarity, and dissonance of the categories or themes was drawn upon to synthesise the interview data.[272] These are defined as convergent (the same and could be collapsed into one), complementary (the categories are different but linked(5)) and dissonant (contradictory). A new ‘discrete’ code was added to retain the essence of the *within* case analysis and ensure that the barriers/enablers identified there were not lost during the synthesis.

The first step was to re-visit the within-case analyses for the RDS and locCRN and refamiliarise with the data. Next a list of sub-categories/categories (henceforth described as categories) related to cross-regional working from the RDS and locCRN interview data was compiled into a matrix (see Table 3.3-2). A process of coding the categories as convergent, complementary, dissonant, or discrete was conducted. This also involved a process of going back and forth between the categories in the matrix and the source data. When a category from, for example, the RDS was found to be supported by a meaning unit/code from the locCRN data, the latter was added to the matrix and labelled (e.g. convergent/dissonant etc)

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[5] An example of a ‘complementary’ code is ‘PPI uncoordinated regionally’; this was an issue for both RDS and locCRN but related primarily to PPI staff in NIHRio and NHS trusts respectively.

appropriately. Next, the convergent and complementary categories were merged into overarching barriers/enablers and given a descriptive label. This made the representation of the categories in the models of knowledge-sharing and collaboration easier.

Table 3.3-3 – Example of matrix of regional barrier/enabler categories for RDS & locCRN

Barrier/enabler categories/sub-categories from RDS/locCRN within case analysis	RDS	CRN	Synthesis code	Merged and re-labelled enabler/barrier categories
1. Silo working		✓	Convergent	Silo working
2. Others not sharing, engaging	✓		Convergent	
3. PPI un-coordinated regionally	✓		Complementary	Need to identify others in a PPI role
4. Need to identify NHS, NIHRio & university PPI		✓	Complementary	
5. Lack of awareness of who has a PPI role	✓		Complementary	
6. Job demands collaboration with non-NIHRio		✓	Complementary	
7. Culture of sharing & collaboration lacking		✓	Discrete	Culture of sharing & collaboration lacking

Step 3 - Apply framework

The merged and re-labelled categories were grouped using the conceptual framework devised from the literature for knowledge-sharing and collaboration (Chapter 2).

Step 4 - Present conceptual models

Conceptual models that shed light on the barriers/enablers to knowledge-sharing and collaboration of NIHRio PPI were presented as diagrams: for regional there were two models, one for the antecedents to knowledge-sharing and collaboration and one for the barriers/enablers to the act of collaboration; for national there was one model. These models contained the merged and re-labelled categories and the concepts from the framework of barriers/enablers constructed from the literature review.

3.3.2 Triangulation of reported regional sharing and collaboration data

To verify the data from the RDS and locCRN PPI staff interview and document review on sharing and collaboration, a process of triangulation was employed. There are four main types of triangulation: theoretical triangulation; data triangulation; investigator triangulation and methodological triangulation.[273] In this project data triangulation (data collected from different sources) and methodological triangulation (data collected through different methods – interviews and document review) was conducted using the three data sets.

The process involved creating a matrix with columns for the data sources and rows for the data (Appendix K). The 'regional sharing and collaboration' categories from the QCA (interview data) and the nodes from the document review were entered into this matrix. The final step was to compare the data from each source to search for discrepancies and agreement in the verbal and written reports of sharing and collaboration regionally.

3.3.3 Synthesis of RDS and CRN resources and funding panel data

In the interviews, details of RDS and locCRN (Chapters 5 and 7) resources and the training, resource needs, skills and experience of funding panel public members were collected (Chapter 6). These data were incorporated into a matrix to identify duplication and opportunities for sharing (Chapter 8).

3.3.4 Supplementary data - Document review

The document review supplemented the interview data by providing further information about the regional NIHR PPI landscape. The data source was the 2016/2017 NIHR PPIE Annual Reports from infrastructure organisations (Table

3.3-3) accessed from the NIHR website.[274] This period was selected to match the interview data collection timepoints.

Table 3.3-4 – NIHR Infrastructure organisations with PPIE Annual Reports

Infrastructure organisation	**Number of units/centres**
Biomedical Research Units/Centres	31
Clinical Research Facilities for Experimental Medicine	19
Health Technology Co-operatives	8
Diagnostic Evidence Co-operatives	4
Collaborations for Leadership in Applied Health Research and Care	13
Blood and Transplant Research Units	4
Health Protection Research Units	13
Patient Safety Translational Research Centres	2

The review did not necessitate a complex review process. PPI activity, provision and collaboration were described under specific headings or in an unstructured narrative format. I devised a data extraction framework from a proportion of the Biomedical Research Centres/Units (BRC/U) reports as it had the largest number of units across England. The framework was tested against the remainder of the BRC/U report and against another NIHRio report and refined/amended accordingly (See Appendix L for example). The framework was created in NVivo structured by the 10 RDS regions, with sub-nodes for the relevant NIHRio and child-nodes for ‘activities’, ‘resources’, ‘collaborating with other NIHR’ and ‘collaborating with other non-NIHR’. The reports were uploaded, and data were extracted into the framework (Appendix M). The data were reported narratively for each region,

A mapping exercise was conducted to identify and display links and collaborations between the NIHRio in the regions. Mapping is a method that ‘seeks to identify, not results, but linkages’ (p76).[275] These linkages can be illustrated textually or visually using specific software. Some examples of the latter are in the study of communication and collaboration in research networks[276] and worldwide scientific collaboration.[277] A simplified form of visual mapping was used to illustrate collaborations regionally. Symbols were used to represent each NIHRio, their resources (patient/public groups and training) using the 10 RDS regions as a footprint. Where appropriate NIHRio were linked to illustrate collaboration and sharing.

Drawing upon the textual and visual data, it was possible to identify regions where there was reported collaboration and sharing and those where no such links were recorded (Chapter 4). The textual data was also used in the triangulation of the RDS and locCRN interview data (Chapter 8).

3.4 Summary and reflections on the project design and procedures

The comparative case study design provided the opportunity to build a picture of PPI provision, resources and the barriers/enablers to regional and national knowledge-sharing and collaboration. Qualitative methods enabled in-depth exploration of the informants' experiences in their roles. NIHR is a complex organisation and the information collected through interviews, documents and websites, and survey provided context to the multiple case study, and aided interpretation of the findings.

A constructivist approach acknowledges the impact of the researcher on the researched and on the data collected. In this project all informants were aware of my role as an RDS senior research methodologist/advisor. Although this did not always facilitate the access I had originally envisaged, mentioning my own experience with the RDS (when appropriate) enabled me to build up a certain level of rapport in the interviews. This was particularly so with the locCRN interviews and resulted in some extremely frank disclosures about PPI, sharing and collaboration. It is possible the RDS informants may have considered me as someone who would judge their work practice rather as 'one of their own', resulting in more guarded responses. Despite this I believe working for the RDS was beneficial, particularly because the shared understanding of NIHR between myself and the informants facilitated discussion and allowed the key issues of sharing and collaboration to be a key focus.

It was beyond the scope of this project to conduct in-depth interviews with PPI leads in every part of the NIHR to explore PPI provision, collaboration and sharing. The inclusion of the annual report document review - where PPI provision, resources and collaboration are recorded – supplemented what was collected from the RDS and locCRN in the interviews and enabled triangulation of the data sets.

In most cases, senior RDS, funding panel and locCRN staff were the gatekeepers to eligible informants. This reliance on a senior member of staff to suggest who best to interview may have introduced some selection bias. However, in the locCRN – where the PPI teams tended to be larger than those in the RDS - this process led to interviews with informants ranging from the PPI Officer to Chief Operating Officer and provided an insight to knowledge-sharing and collaboration from the grass roots to strategic level.

The following chapters report the comparative case study findings, beginning with the document review (Chapter 4), the RDS (Chapter 5), funding panel public members (Chapter 6) and locCRN interviews (Chapter 7). The penultimate chapter is a synthesis of all data (Chapter 8). Finally, the findings are discussed in relation to the literature and recommendations made regarding a streamlined model of NIHR PPI and improving knowledge-sharing and collaboration.

Chapter 4: A regional picture of NIHR PPI sharing and collaboration: document review and mapping

4.1 Introduction

As demonstrated in the introduction to this thesis, NIHR is a complex organisation with many component parts. The Going the Extra Mile report called for building partnerships and joint working regionally, within and beyond NIHR boundaries.[79] However, what opportunities are there for joint working regionally? What is the regional landscape, in terms of the number and type of NIHR infrastructure organisations (NIHRio)? Does each NIHRio have resources, and do they already share and collaborate regionally? This chapter addresses these questions, and supplements the in-depth data reported in the subsequent chapters on resources, sharing and collaboration.

In this chapter the data source and methods are briefly outlined followed by the maps of each Research Design Service area and a commentary on PPI provision, sharing and collaboration. The chapter concludes with a summary reflecting on the findings of this review.

4.2 Data source

Nine types of NIHRio (Table 4.2-1) produce annual reports[278] (as do the RDS) of resource use, collaborations and progress towards achieving their PPI Strategy. They are required to report their activities, outcomes and any partnerships and collaborations. This is a useful information source to explore sharing and collaboration regionally.

Table 4.2-1 – Number and purpose of NIHR infrastructure organisations and research units with PPI

BRC	**Biomedical Research Centres** (conduct and support translational research)	11	Each covers a range of health conditions
BRU	**Biomedical Research Units** (conduct and support translational research)	20	• Cardiovascular Hearing • Dementia Gastrointestinal • Musculoskeletal Nutrition • Respiratory
PSTRC	**Patient Safety Translational Research Centres** (conduct and support research to investigate ways to improve the safety, quality and effectiveness of NHS services)	2	Each covers a range of health conditions
CRF	**Clinical Research Facilities for Experimental Medicine (**provide purpose-built environments for patient-centred research)	19	Each covers a range of health conditions
CLAHRC	**Collaborations for Leadership in Applied Health Research and Care** (conduct applied health research that is transferable across the NHS)	13	Each covers a range of health conditions
HTC	**Healthcare Technology Co-operatives** (develop concepts, demonstrate proof of principle and devise research protocols for new medical devices and healthcare technologies)	8	• Brain injury • Cardiovascular • Colorectal • Devices for dignity • Enteric • Mind • Trauma • Wound
DEC	**Diagnostic Evidence Co-operatives** **(**centres of expertise to catalyse the generation of evidence on in vitro diagnostic medical devices)	4	Each covers a range of health conditions
BTRU	**Blood and Transplant Research Units** (supports NHS Blood & Transplant and provides high quality research evidence**).**	4	• Donor health & genomics • Stem cells & immunotherapies • Organ donation & transplantation • Red blood cell products
HPRU	**Health Protection Research Units** (supports Public Health England in delivering its objectives and functions for public health priority areas)	13	• Blood borne & sexually transmitted infections • Chemical & Radiation Threats & Hazards • Emergency Preparedness & Response • Emerging & Zoonotic Infections • Environmental Change & Health Evaluation of Interventions • Gastrointestinal Infections • Healthcare associated infection & antimicrobial resistance • Health Impact of Environmental Hazards • Immunisation • Modelling Methodology • Respiratory Infections

For brevity the abbreviations for the NIHRio from Table 4.2-1 are used in Section 4.4.

4.3 Methods

A document review (see Chapter 3 for full methods) was conducted drawing upon the information from the 2016/2017 NIHRio and the RDS PPIE Annual Reports accessed from the NIHR website. Data regarding PPI activity, provision and collaboration were extracted into a framework developed in NVivo. Using the 10 RDS regions as a footprint the different types of NIHRio were mapped and represented by symbols. Collaborations and links were illustrated with lines between organisations.

The local Clinical Research Networks (locCRN) do not contribute to these reports and the research schools have not produced reports for 2016/17; they are only added to the maps when reported by other NIHRio. Similarly, the Academic Health Science Network is not an NIHR body but has been added to the diagrams when reported.

4.4 Document review and mapping

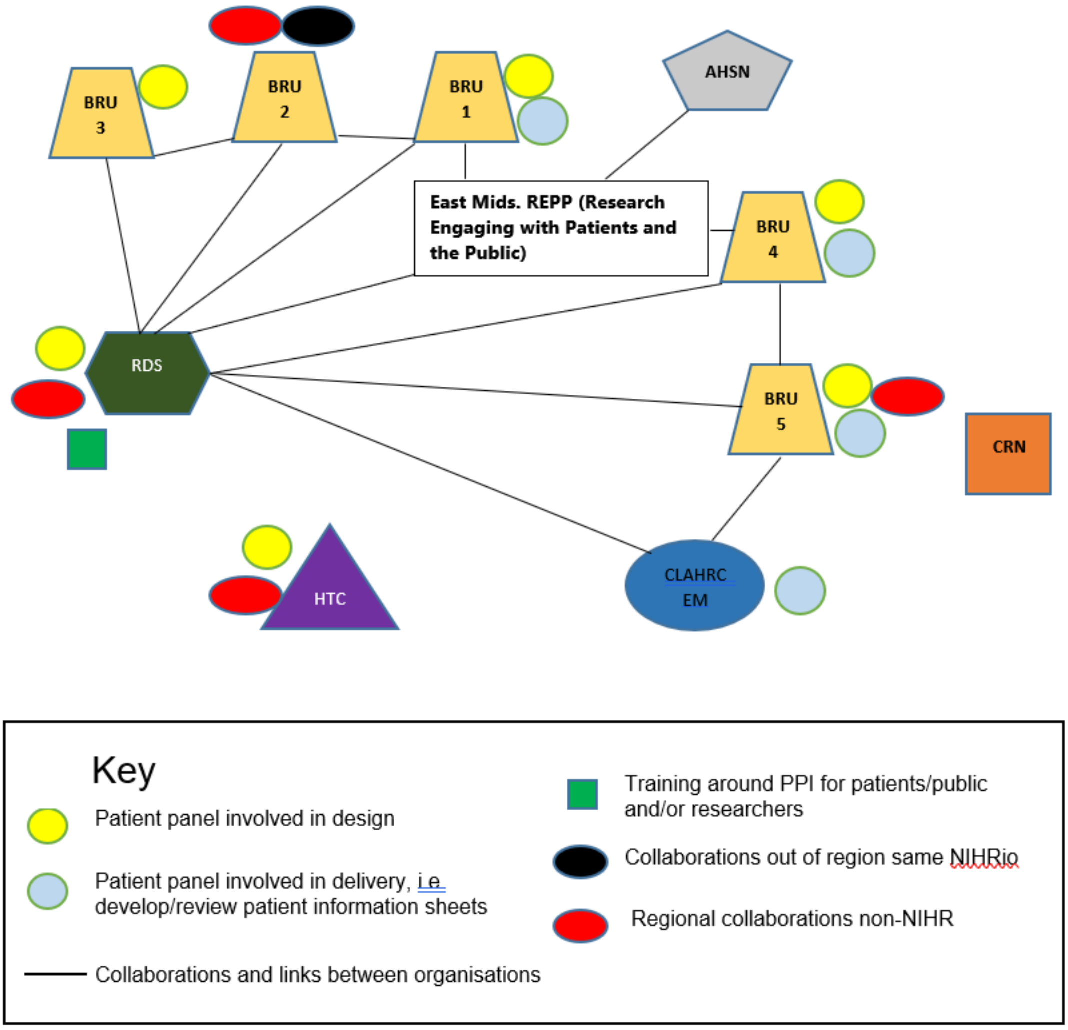
Table 4.4-1 provides an overview of the number of NIHRio (including the RDS and locCRN) in each region and how many have their own patient/public group. The number who had training resources may be an underestimate if they were not specifically referred to in the report.

Table 4.4-1 – Number of NIHRio in each region, patient group and training resources

Region	Number of NIHRio	Number with pt/public groups	Number with training resources
East Midlands	9	7	1
East of England	8	5	3
North East	7	4	2
North West	12	8	3
South Central	12	3	1
South East	3	1	0
South West	9	6	2
West Midlands	7	3	0
York and Humber	11	5	0
London	36	19	6

Brief summaries, describing the resources and drawing upon examples of sharing and collaboration, are given after each diagram.

East Midlands

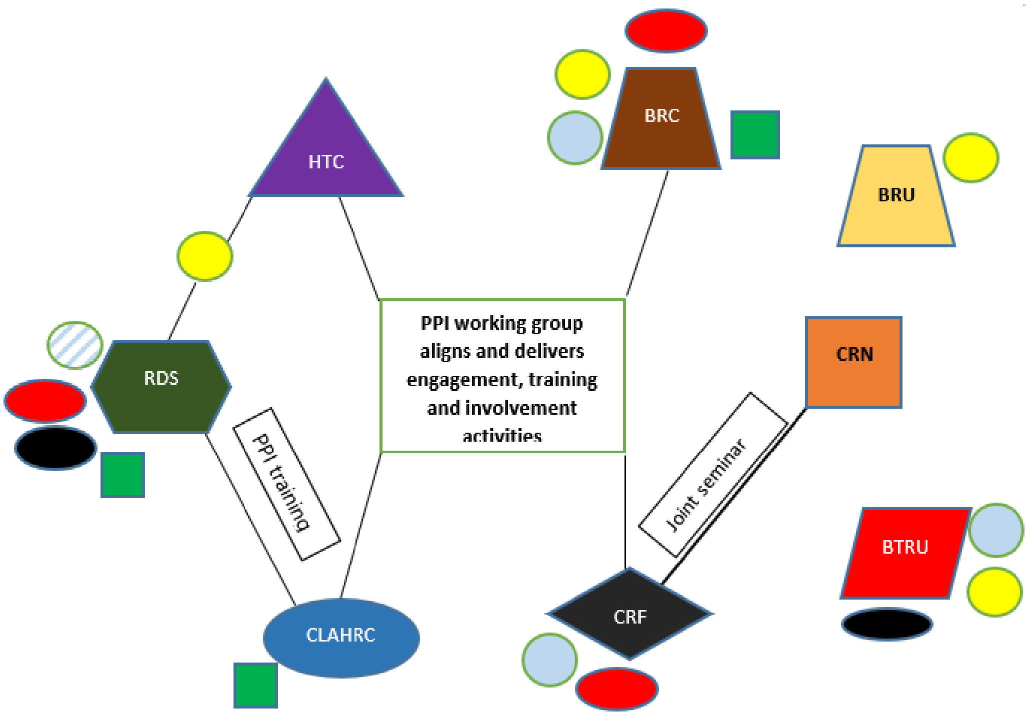


East Midlands had nine NIHRio. The diagram illustrates the RDS as central in terms of connections and collaborations. Most of the NIHRio were linked with only the locCRN and the Healthcare Technology Co-operatives (HTC) on the periphery. Four NIHRio reported their involvement in the long established REPP (Research Engaging with Patients and the Public) group managed by the region’s Academic Health Science Network (AHSN), to co-ordinate PPI activity across the region. Three of the five BRU collaborated with each other to maximise resources and undertake PPI jointly. One Biomedical Research Unit (BRU) collaborated with a BRU in another region though no further description was given

Led by BRU5, a Public Involvement Training Sharebank had been developed in collaboration with others regionally (including a local university; BRU4, RDS, Collaborations for Leadership in Applied Health Research and Care (CLAHRC)). The aim was to 'create learning and sharing experiences to improve the extent and quality of public involvement in research' [279] (p48).

Regarding resources, seven NIHRio had their own patient groups. To address age gaps in their own patient group the HTC accessed PPI through a local trust and community groups. BRU2 sought patient involvement through a national charity's PPI network. Only the RDS reported lay reviewer training but there was no mention of sharing this with other NIHRio.

East of England



Key

🟡 Patient panel involved in design

🔵 Patient panel involved in delivery, i.e. develop/review patient information sheets

▨ Recruit ad hoc/signpost researchers to patients to comment on delivery

—— Collaborations and links between organisations

🟩 Training around PPI for patients/public and/or researchers

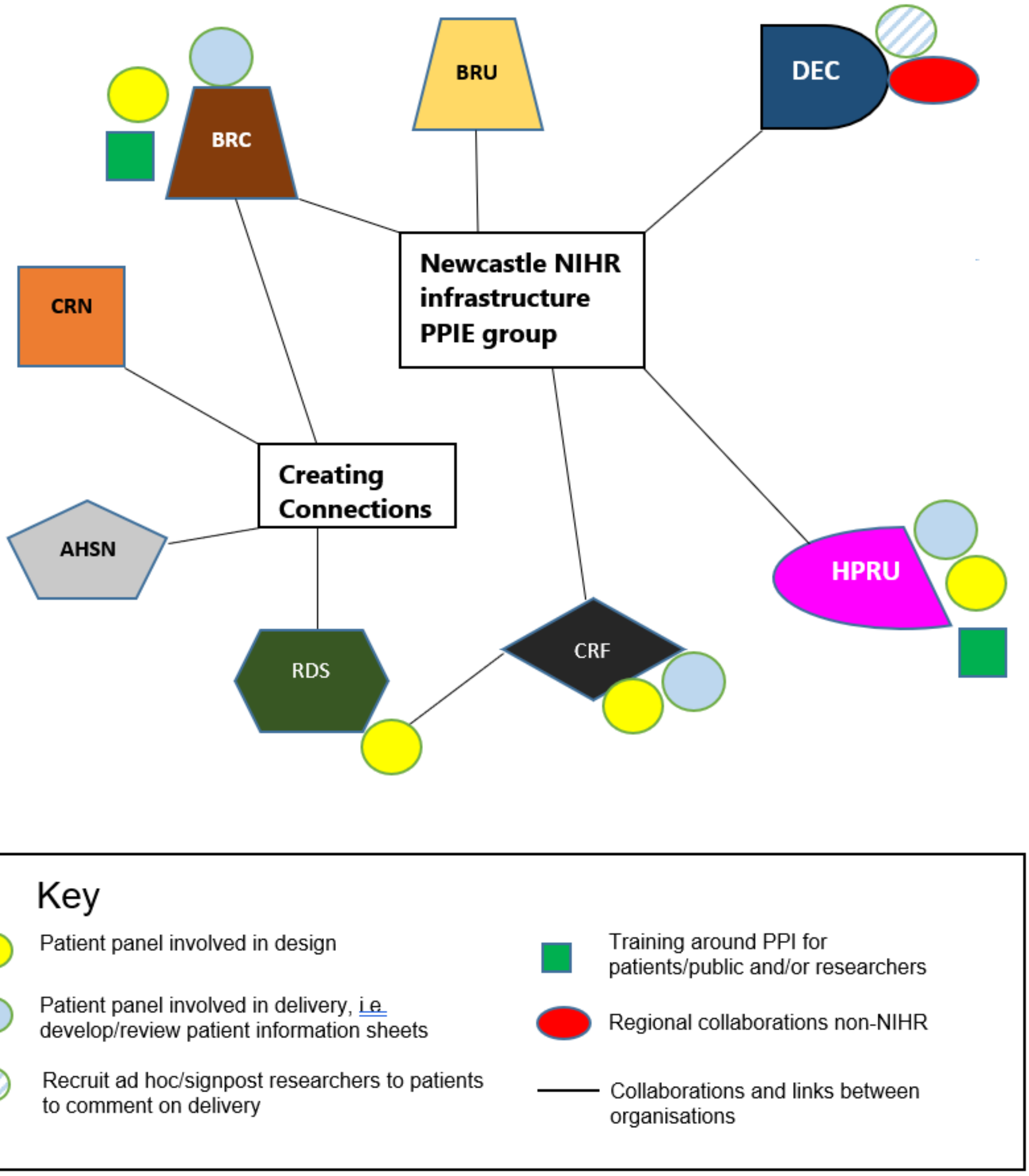
⚫ Collaborations out of region same NIHRio

🔴 Regional collaborations non-NIHR

East of England had eight NIHRio. Four of these are connected through a PPI working group, whose aim is to align and deliver training and involvement activities. The RDS report talks of the Public Involvement Research Partnership Group and it is difficult to know whether this is the same group. There was evidence of joint working on PPI in patient information and consent processes, PPI training, and the use of social media in research. The RDS had collaborated with another RDS on an INVOLVE commissioned project around co-production. The Biomedical Research Unit (BRU) and Blood an Transplant Research Unit (BTRU) did not report any links or collaborations with NIHRio in the region but the latter had worked with their counterparts on a Trainees' Day and were contemplating future joint work around PPIE.

The RDS had established connections and signposted their clients to patient groups outside NIHR. The Clinical Research Facility (CRF) described the support of Patient Research Ambassadors from local NHS Trust(s) with training and events and peer review of study protocols.

North East

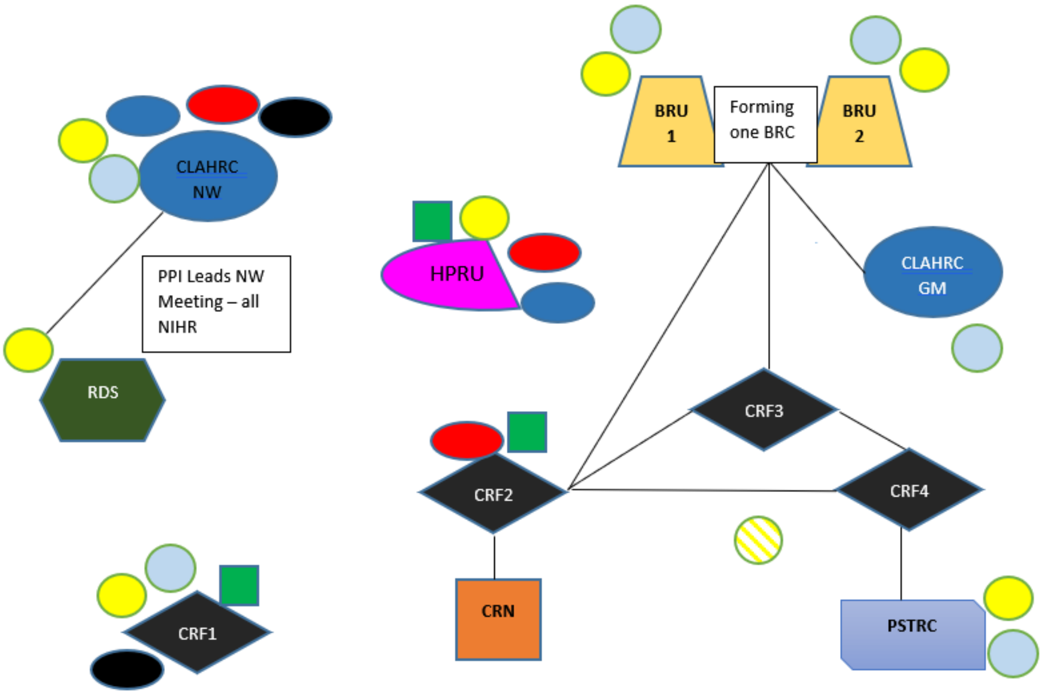


In the North East there were seven NIHRio. The diagram indicates the Newcastle NIHR Infrastructure PPIE Group as quite central and five NIHRio reported membership. It is unclear from the reports why two groups are required, though the Creating Connections Group was described as involving wider stakeholders across the region. These groups are described as a place to share 'learning and best practice' [279] (p15).

Four of the NIHRio had patient groups and the Clinical Research Facility (CRF) reported ‘support’ from the RDS Consumer Panel. The Diagnostic Evidence Co-operative (DEC) worked with the local NHS Trust PPI Lead to convene groups on an ad hoc basis for PPI in research delivery.

The Biomedical Research Centre (BRC) and Health Protection Research Unit both offered training to researchers and patients/public in a PPI role. There was no reports of sharing training.

North West



Key

🟡 Patient panel involved in design

○ Patient panel involved in delivery, i.e. develop/review patient information sheets

▨ Recruit patients ad hoc to comment on design

—— Collaborations and links between organisations

🟩 Training around PPI for patients/public and/or researchers

⚫ Collaborations out of region same NIHRio

🔴 Regional collaborations non-NIHR

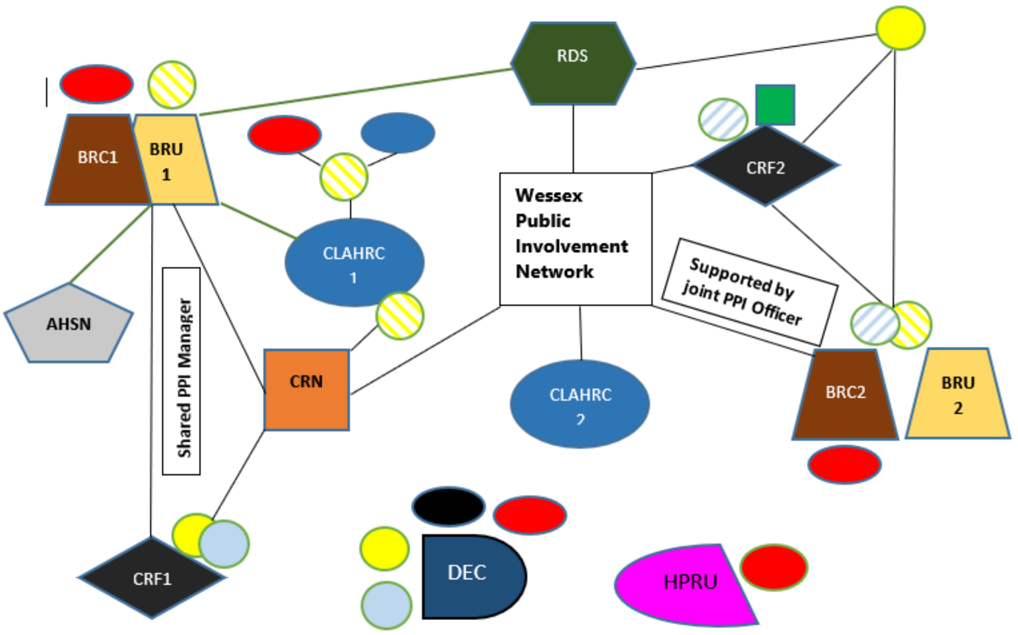
🔵 Collaborations with other NIHRio out of region

There were 12 NIHRio in this region. The diagram shows two clusters. The largest cluster - with two Biomedical Research Units (BRU), Collaborations for Leadership in Applied Health Research and Care GM (CLAHRC) and three Clinical Research Facilities (CRF) - were developing shared PPI strategies, sharing of best practice, and exploring opportunities for greater collaboration. CRFs 2-3 and 4 were funding a Public Programmes Team to work with them and the Patient Safety Translational Research Centre (PSTRC) to enhance PPI practice across the CRFs and wider structure.

In the second smaller cluster with the other CLAHRC, regionally they linked with third sector organisations, but their collaborations tended to be outside of the region with another CLAHRC, other NIHR and non-NIHR partners. They were building a PPIE network linking with the RDS patient group and those in local NHS trusts and had launched a strategic network for PPI Leads for the North West. Neither of these were reported by the NIHRio in the larger cluster.

Eight of the 12 NIHRio had their own patient groups. The Health Protection Research Unit's (HPRU) patient panel was established in partnership with a local university. Of those without a dedicated patient group, the CRF2 had sought patient involvement in design and delivery through national charities. CRF1&2 and the HPRU reported running training sessions for patients and researchers. There was no mention of sharing. The HPRU had held a PPI education day for researchers with a counterpart.

South Central



Key

- ● Patient panel involved in design
- ● Patient panel involved in delivery, i.e. develop/review patient information sheets
- ▨ Recruit patients ad hoc to comment on design
- ▨ Recruit ad hoc/signpost researchers to patients to comment on delivery
- —— Collaborations and links between organisations
- 🟩 Training around PPI for patients/public and/or researchers
- ● Collaborations out of region same NIHRio
- ● Regional collaborations non-NIHR
- ● Collaborations with other NIHRio out of region

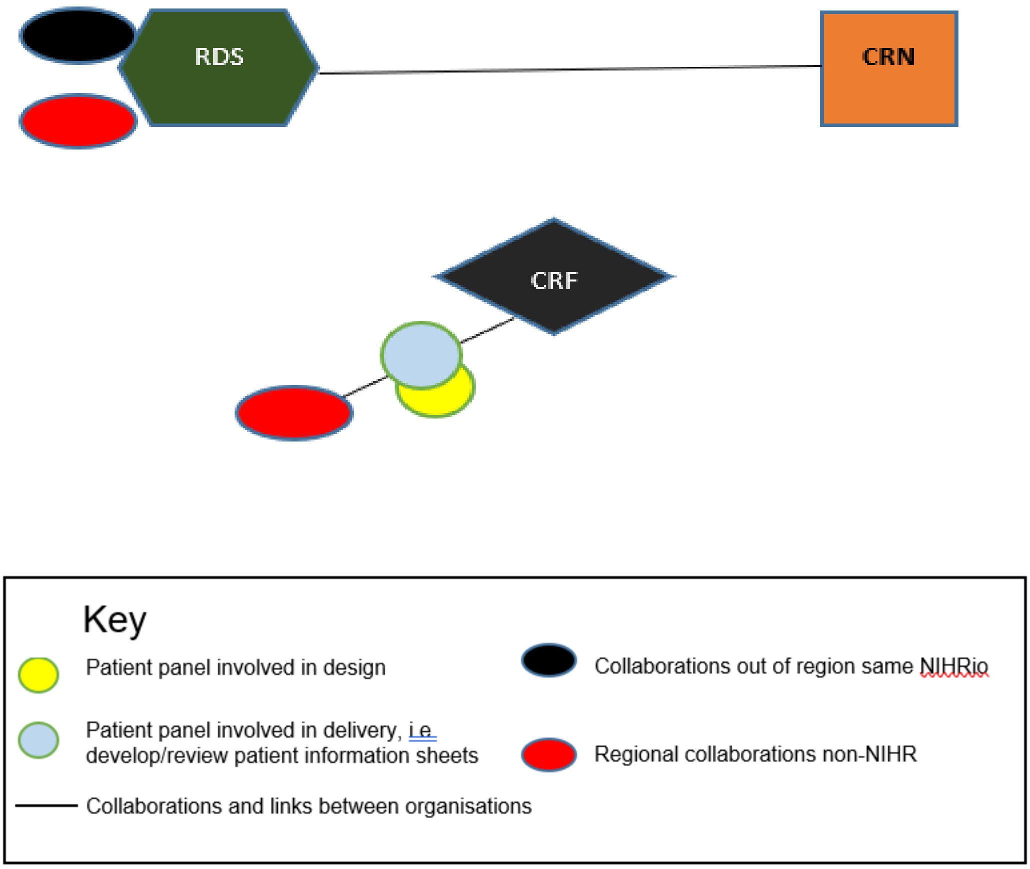
This region, with 12 NIHRio, was characterised by the development of several patient groups/databases/registers for PPI. The RDS, Biomedical Research Centre 2 (BRC) and Clinical Research Facility 2 (CRF) convened a young adult group and the same BRC, in conjunction with BRU2, set up a database of patients/public willing to be involved. BRC1/BRU1 had established Patients Active in Research, a matchmaking website and patient register for researchers who need access to patients for PPI. CRF1 had convened the Patients in Research Group with an aim to ‘involve patients and the public in as many areas of the project cycle as possible’. In collaboration with unspecified NIHRio and the local university, Collaborations for Leadership in Applied Health Research and Care 1 (CLAHRC) was developing a database of PPI contacts to be called upon for specific projects.

The locCRN was much more integrated in the region than evidenced in other regions and apart from the links illustrated had support from patient groups through one of the CLAHRC and from CRF1. CRF2 did not appear to have an established patient group but had involved patients on an ad hoc basis for a particular study.

There was some collaboration on PPI training. Others had training resources but there were no reports of sharing regionally. The Diagnostic Evidence Co-operative (DEC) had held joint PPI workshops with a counterpart. Both the DEC and the Health Protection Research Unit (HPRU) appeared to have little connection to NIHRio in the region. There were shared PPI posts, CRF2/BRC2/BRU2 had a joint PPI Officer as did BRC1/BRU1.

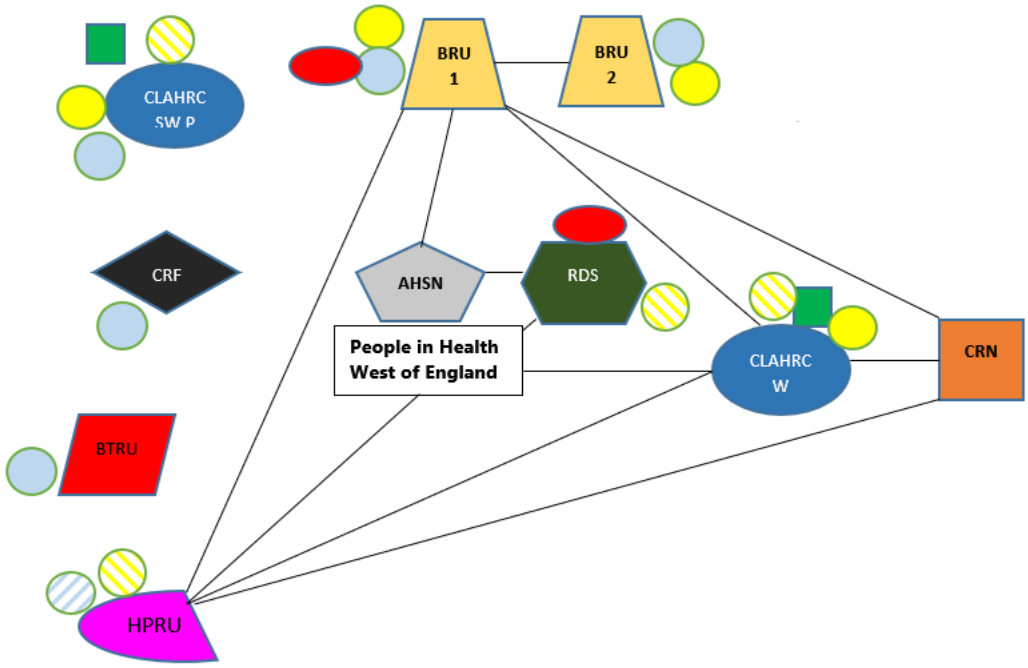
Another characteristic was the Wessex Public Involvement Network established to ‘strengthen our PPI activities and enable joint working on key issues outlined in NIHR’s Going the Extra Mile” report’ (p25). Five NIHRio were members. Six of the NIHRio reported they were part of this network.

South East



The South East had three NIHRio. In terms of patient groups, the RDS draw upon those facilitated by an NHS trust and the local university. The Clinical Research Facility (CRF) has links to an NHS trust patient group who appear to be involved primarily in research design but could extend to delivery. The RDS report describes collaborating with the locCRN to conduct joint PPI workshops and with another RDS to develop a framework for public involvement at the design stage.

South West



Key

- 🟡 Patient panel involved in design
- 🔵 Patient panel involved in delivery, i.e. develop/review patient information sheets
- ▨ Recruit patients ad hoc to comment on design
- — Collaborations and links between organisations
- ▨ Recruit ad hoc/signpost researchers to patients to comment on delivery
- 🟩 Training around PPI for patients/public and/or researchers
- 🔴 Regional collaborations non-NIHR

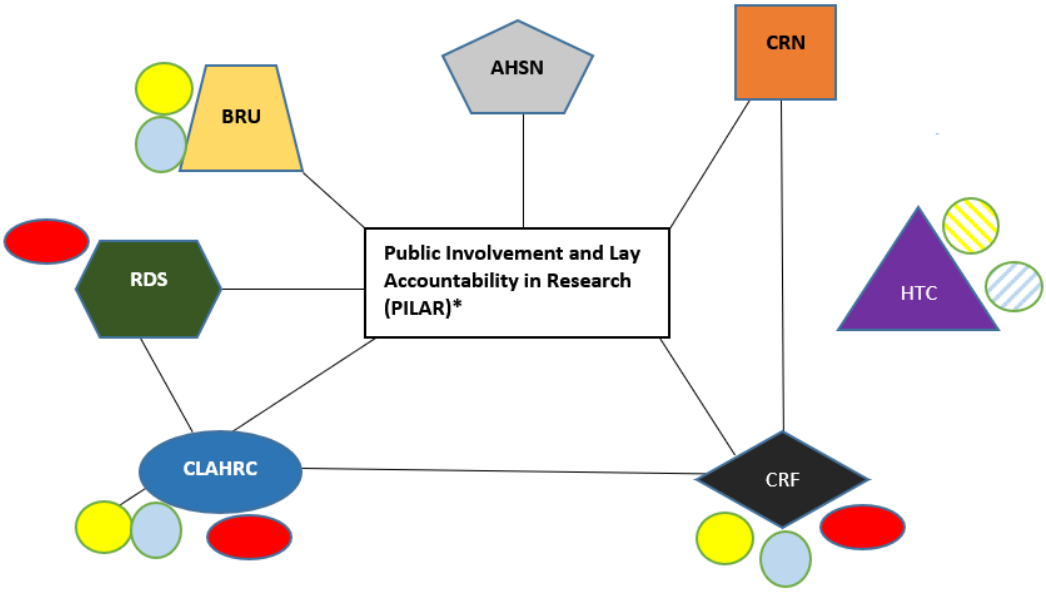
The South West is a large geographically dispersed region with nine NIHRio. Four are linked through the People in Health West of England Group (PHWE) and the Academic Health Service Network. This group is described as providing ‘access to public contributors and shared training for public contributors and staff’ (p21).[280]

Six had patient groups. There was sharing of patient groups between the Biomedical Research Units (BRU). The two Collaborations for Leadership in Applied Health Research and Care **(**CLAHRC), the Health Protection Research Units (HPRU) and the RDS recruit patients on an ad hoc basis for involvement in research design and or delivery. The RDS reports that, due to the geography of the area, they access patient involvement via ‘local support groups, charities or other networks’ (p20).[280]

CLAHRC-W runs a PPI learning and development programme that attracts attendees from outside of the area. CLAHRC-SW runs ‘clinics’ for their staff around incorporating PPI into their projects. Neither report sharing with other NIHRio.

Again, the locCRN has more links to other NIHRio than was demonstrated in other regions. CLAHRC-SW, the Clinical Research Facility (CRF) and Blood and Transplant Research Units **(**BTRU) do not report links to the others in the region or sharing of resources.

<u>West Midlands</u>



Key

🟡 Patient panel involved in design

🔵 Patient panel involved in delivery, i.e develop/review patient information sheets

▨ Recruit patients ad hoc to comment on design

▨ Recruit ad hoc/signpost researchers to patients to comment on delivery

🟩 Training around PPI for patients/public and/or researchers

🔴 Regional collaborations non-NIHR

🔵 Collaborations with other NIHRio out of region

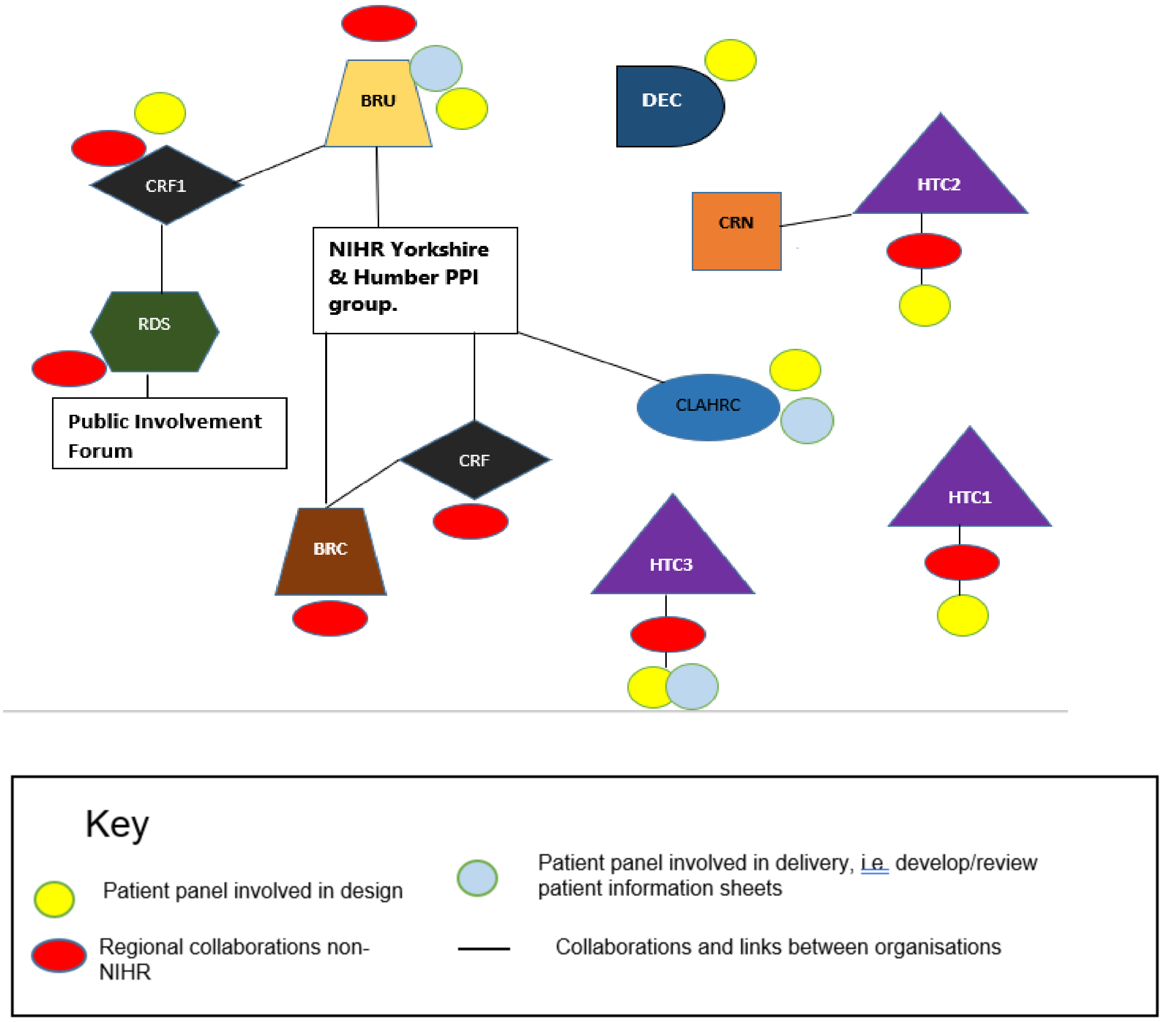
— Collaborations and links between organisations

West Midlands had seven NIHRio. The regional group, PILAR (Public Involvement and Lay Accountability in Research) was central to PPI and all but one NIHRio reported links. This group's purpose is to 'share best practice and develop strategies to overcome barriers to effective involvement of patients and the public in the region' (p27).[281]

Three NIHRio had patient groups involved in both design and delivery. The RDS seek PPI through three established university patient groups in the region. The Clinical Research Facility (CRF) patient group(s) had supported the CRN Research Ambassador Initiative, and were collaborating with locCRN and a local hospital to deliver PPIE programmes, and with the Collaborations for Leadership in Applied Health Research and Care **(**CLAHRC), NHS partners and the locCRN to 'maximise PPIE opportunities' (p7).[282] The CLAHRC had been working with universities to ensure 'meaningful PPI' in research' (p27) and reported linking in with the RDS for practical support with PPI.[281]

The Healthcare Technology Co-operative (HTC), who access existing patient groups through charities, did not report any links or collaboration with NIHRio.

York and Humber



York and Humber had 11 NIHRio. From the reports, the PPI landscape regarding sharing and collaboration appeared more fragmented than in other regions. There was a regional PPI group, yet this was mentioned by only three NIHRio and there was little detail. The RDS report also talked about a Public Involvement Forum but this appears to be primarily for lay members rather than other NIHRio PPI Leads.

Five NIHRio had a patient group to input into the design and/or delivery of studies. The Biomedical Research Unit (BRU) and Clinical Research Facilities (CRF) also accessed patient involvement through a number of non-NIHR sources, such as local councils, universities and NHS trusts. All three Health Technology Co-operatives (HTC) accessed established patient groups through charities, local trusts or universities and were building up networks through other sources rather than starting new groups. Only one of the HTCs (2) reported working with the locCRN to build up these networks.

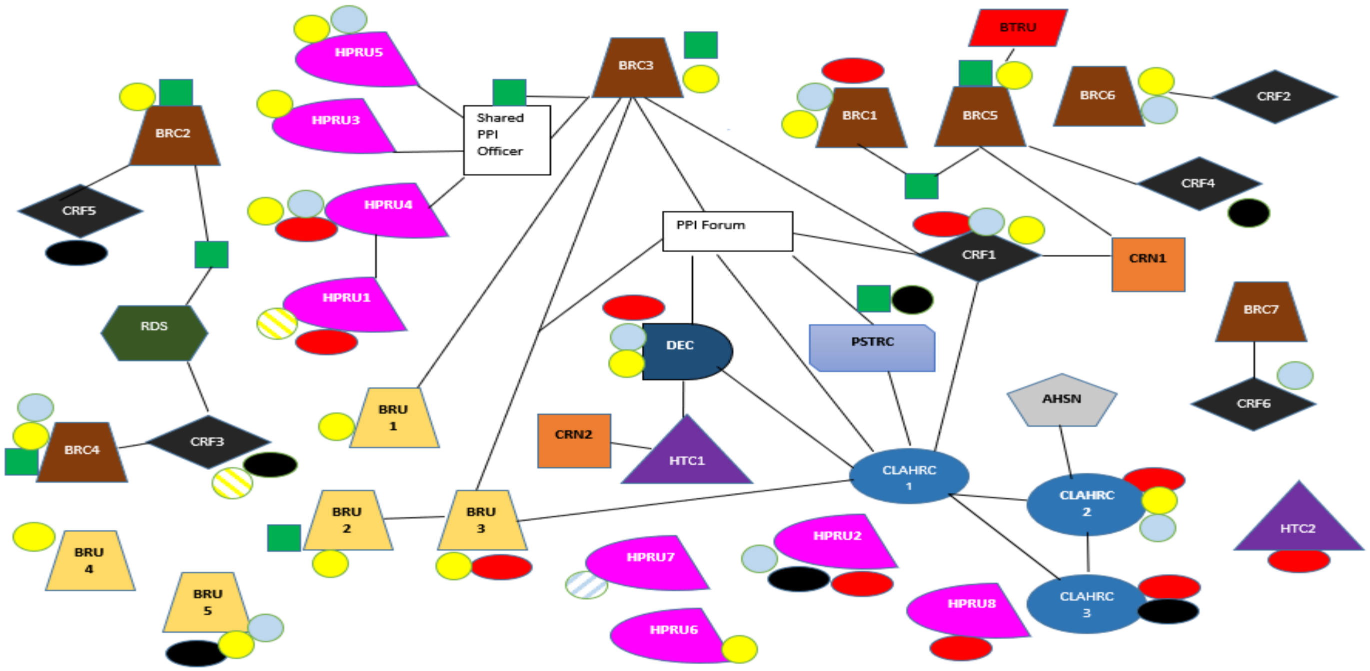
London

London portrays a complex picture with a large number of NIHRio in the region. There is little sharing of patient groups across the region, apart from between a few of the Clinical Research Facilities (CRF) and Biomedical Research Centres (BRC). Two BRC host regular PPI training for researchers; the RDS collaborated with another BRC to deliver PPI workshops.

There are two clusters (links of more than two NIHRio): in the largest cluster BRC3 and Collaborations for Leadership in Applied Health Research and Care 1 (CLAHRC) are central in connecting a range of different NIHRio. Other features of this large cluster is a PPI Forum - of which six of the NIHRio are members - and three Health Protection Research Units (HPRU) and a BRC share a PPI Officer.

In a second smaller linear cluster the RDS provided PPI training for BRC researchers and one CRF. For a number of others there are no links or collaborations with other NIHRio in the reports. The three CLAHRCs in the region collaborate on various events; and described a knowledge-sharing and public engagement event involving CLAHRCs outside of the region. Both locCRNs also appear to be on the periphery.

London



Key

🟡	Patient panel involved in design
🔵	Patient panel involved in delivery, i.e. develop/review patient information sheets
▨	Recruit patients ad hoc to comment on design
▨	Recruit ad hoc/signpost researchers to patients to comment on delivery
🟩	Training around PPI for patients/public and/or researchers
⚫	Patient involvement source not given
⚫	Collaborations out of region - same NIHR organisation
🔴	Collaborations non-NIHR
—	Collaborations and links between organisations

4.5 Summary

The findings from this document review and mapping exercise demonstrates the variability across the NIHRio particularly the degree of collaboration and sharing within regions.

Based on the annual reports, in many regions NIHRio had their own patient groups involved in the design and/or delivery of research. Others obtained this input from national groups (often linked to charities), from local trusts or occasionally universities. Sometimes PPI was sought on an ad hoc basis to meet the needs of a specific proposed or funded project.

There were examples of NIHRio sharing training (running joint events or inviting other NIHRio) and patient groups supporting a team from another NIHRio. However, some NIHRio made no mention of sharing or enabling others access to their patient groups. The training – particularly around PPI, how to involve patients, training involved patients in reviewing proposals or study materials – could, in most cases, be shared. Sharing of patient groups is arguably not as straightforward, particularly as many are condition or topic specific groups and this may have been the reason why many of the Health Protection Research Units – which are condition specific – sought PPI from outside of the region. Nevertheless, clients of the local RDS or researchers from another part of the country may benefit from the input of these patient groups.

There is a mixed picture across the ten regions, particularly in terms of the cross-NIHRio collaboration. Commonly, one unifying element regionally is the existence of a PPI-focused group that a number of the NIHRio are part of. Within some regions there may be increased collaboration through these groups, but it was often difficult to determine when the reports used different names for the groups. The role of these groups varies by region: in some their remit is to co-ordinate PPI activities or to deliver training and involvement. West Midlands was the best example with their

PILAR (Public Involvement and Lay Accountability in Research) Group; where, unlike others they had managed to engage all but one of the NIHRio as members.

The integration of the RDS and locCRN in the regions also varied. In one the RDS was a central feature with strong links to the other NIHRio, collaborating on events and sharing training. In contrast, in some regions the RDS was linked to only one NIHRio. The picture was similar for the locCRN and the Collaborations for Leadership in Applied Health Research and Care – in some regions they were integrated and in others they were on the periphery. Diagnostic Evidence Co-operatives, Health Technology Co-operatives, Blood and Transplant Research Units and Health Protection Research Units, with some exceptions, tended not to collaborate or share with other NIHRio. In some cases, they were more likely to work with the same organisation in another region.

In some regions the same NIHRio worked together on PPI, for example Biomedical Research Units, collaborated to maximise PPI resources. Some Biomedical Research Centres/Biomedical Research Units and Clinical Research Facilities were beginning to develop a joint PPI strategy. In regions where initiatives such as PPI forums or shared posts have been implemented it is not known whether these have been evaluated. There appears to be no standard or model of how best to operationalise and deliver PPI, particularly on a collaborative and sharing basis.

The main aim of this document review was to gain an understanding of the resources, sharing and collaboration at a regional level over a one-year period. The findings demonstrate the variability in the degree of regional collaboration and sharing. However, one limitation is it is likely that the review has not fully captured NIHRio resources which would only be mentioned in the one-year reporting period if they had shared or developed a resource.

A secondary aim was to triangulate this data with that collected through in-depth interviews with RDS and locCRN PPI leads as a form of verification. In Chapter 8 the review findings will be synthesised with the data collected from the case study on PPI provision, sharing and collaboration, and the triangulation reported.

The next chapter reports the within-case analysis of the RDS PPI leads interview data exploring PPI provision, and knowledge-sharing and collaboration both regionally and nationally

Chapter 5: A shift in PPI provision and a disordered regional landscape? views from the Research Design Service

The NIHR Research Design Service (RDS) is situated near the beginning of the research spectrum, the stage where ideas are developed and formulated into robust funding applications. Data from RDS staff addresses the research design component of the question ‘What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHIR?’. It provides an insight into the PPI advice and support they provide to those who consult the service, and the resources they hold. Exploring their experience of sharing and collaborating with others within and outside of NIHR both regionally and nationally addresses the second question ‘What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?’.

5.1 The case – the Research Design Service

In 2008 the NIHR funded ten RDSs in England for an initial five-year period to support academics, NHS staff and small and medium enterprises to develop their research ideas into scientifically robust funding applications and to build a team of investigators (See Chapter 1). They also provide advice and support on how to involve patients and the public in both study design and conduct. The RDS commissioning brief requested a PPI plan, the strength of which in ‘ensuring public and patient involvement in all stages of the research process’ (p7)[283] was one of the selection criteria. More specific information on the role of the RDS in relation to PPI was provided later in a national annual report.[280] This was to provide advice to RDS clients on how to:

- meaningfully involve patients and the public in the design and development of a funding application as well as for the duration of the study

- access patients early in the development phase

- access a patient or lay person to be a co-applicant on a funding application and/or patients to potentially have involvement for the duration of the study.

Since 2008 there have been two further rounds of re-tendering for RDSs and all ten are now funded until 2023. Their geographical location maps on to the previous 10 Strategic Health Authority areas of East of England, East Midlands, London, North East, North West, South Central, South East Coast, South West, West Midlands, and Yorkshire and Humber.

In 2015 a new contract to deliver the services of INVOLVE in partnership with the RDS was awarded. In an INVOLVE newsletter [284] it was stated.

> ‘Our new partnership with the Research Design Services is starting to take shape and through that partnership working we are now working collaboratively to support the development and co-ordination of effective regional patient and public involvement (PPI) networks which make best use of effort and resources increasing regional to local connectivity to extend and deepen PPI.’ *p1*

This is a key development in the history of the RDS and in terms of sharing and collaboration an important avenue to explore in this thesis.

In the following sub-sections, a brief outline of the identification and recruitment strategy and research methods specific to the case study are given. This is followed by a description of PPI provision in the design of health and social care research offered by the NIHR RDS and data on informants’ views and experiences of, and opportunities for, sharing and collaboration. A website content review of the resources available is also included. The sub-section concludes with a summary of the findings. This data, along with that from other parts of NIHR, will be synthesised in Chapter 8.

5.1.1 *Identification and recruitment of case informants*

The appropriate informants for this case study were the PPI Leads within each RDS. As I worked for RDS North East at the time of data collection I was cognisant of its PPI structure and provision and considered it unnecessary to interview the PPI lead. For this reason, nine of the ten RDSs in England were contacted. The PPI Leads were emailed directly; if their name was not available the email was sent to the Director or a generic RDS email address (see Chapter 3).

5.1.2 *Data collection*

A broad topic guide (see Appendix I) was used to explore the role of PPI and PPI activities within the RDS. This guide evolved over the course of the interviews as new topics emerged. It was decided to introduce the RDS/INVOLVE contract and One NIHR later in the interview. If these were mentioned spontaneously by the informants, this could be a measure of how dominant both were in the working lives of the informants.

The website content review was conducted immediately following interview data collection. The review entailed a search of each RDS website to document resources available to visitors to the site, such as downloadable documents or web links to other information or support.

5.2 Description of RDS PPI provision

5.2.1 *Informants*

Nine RDSs were contacted by email (two PPI leads, two Directors and five generic RDS team addresses). The PPI leads responded and the two Directors and four RDS teams forwarded the email to the PPI Lead. As one of the RDS teams did not respond, the Director’s email address was obtained, and they were contacted. This Director forwarded the email to the team asking that someone respond, but even following this intervention there was no response.

Telephone interviews were conducted between May and November 2017 with one person in a PPI role in each eight of the nine RDSs contacted. Four were solely PPI advisors and four had a dual PPI/general methodologist advisor role. Interview duration was on average 37 minutes, and between 15 and 57 minutes.

Team

The number within each RDS with a PPI remit ranged from two to five people (Table 5.2-1). The structure tended to be a PPI Lead with one to four PPI advisors; in most cases the PPI advisors were in a different geographical area within their RDS patch. The two main types of team composition were: a PPI Lead and others working solely in a PPI capacity or PPI Lead with others in a dual PPI/Specialist Methodological advisor role. For around half of those interviewed (primarily PPI leads) their role was purely PPI; the remainder were PPI/methodological advisors. All of those interviewed had a research or academic background and this was the case for the wider PPI team, apart from one exception where a PPI administrator also provided advice. The RDS NE had a slightly different team composition, with a PPI Lead/Methodological advisor and a lay PPI advisor. In the quotations PPI Leads/Advisors will be labelled as 'PPI/A' and PPI/General Methodologists as 'PPI/GM'. To avoid deductive disclosure[285] different informant numbers have been used in each new sub-section.

Table 5.2-1 - Team composition in each RDS

Number in dedicated PPI Role in each RDS	PPI Team composition in each RDS
4	PPI Lead and PPI Advisors (3)
2	PPI Lead and PPI/Specialist Methodologist Advisor
5	PPI Lead (1) and PPI/Specialist Methodologist Advisors (4)
3	PPI Leads
2	PPI Lead and PPI Advisor
5	PPI Lead, PPI Advisors (3), PPI admin
4	PPI Leads
3	PPI Lead and PPI Advisors (2)
2	PPI Lead and PPI Advisor

The total whole time equivalent of dedicated PPI staff time varied across RDSs from 0.5 to 1.4. Most informants said they would like more time to devote to PPI, either for themselves personally or across their team. One informant described their hope for PPI provision beyond that of supporting RDS clients with PPI in their funding applications.

> *'I'm making an argument to have an advisor extended … because I think then that gives you time to actually do something other than just responding to other people's requests. You know, so develop training, develop materials, develop support erm and try and build a community which is something I'm trying to do and not being very successful.' RDS 01 – PPI/GM*

Some of the larger RDS regions had been split into RDS hubs and when informants referred to their 'region' this was the part they covered. Therefore, when they refer to regional PPI this may not always encompass the full RDS region.

5.2.2 PPI provision in RDS

This sub-section outlines the role of the RDS PPI Leads, PPI provision, resources and activities, and what clients could expect in terms of support. The website resources, training, access to patients/public are listed in Table 5.2-2 and described in greater detail in the subsequent sub-sections.

Advice on PPI

In the majority of the RDSs there had been a move to a model of generalist and/or specialist advisors (such as health economists and statisticians) to provide what was defined as 'basic' PPI advice. This was a means to manage a busy workload and saved the PPI staff a considerable amount of time.

> *'The general advisors are able to look at a project and highlight just quite basic PPI issues without it having to come to one of us. And that means our workload is manageable. Rather than having to radically, dramatically contribute to each application.' RDS-01- PPI/GM*

Table 5.2-2 - Research Design Service Resources

RDS	**Website Resources – documents & links**			**Training**		**Access to patients/public**	**RDS PPI Groups/individuals**
	Own	**Handbook**	**INVOLVE**	**Researchers**	**Lay people**		
01	X	✓	X	X	X	X	X
02	X	✓	X	✓	X	User group directory/database	One/two in face to face mixed panel
03	X	X	X	X	X	X	X
04	X	X	✓ (3)	X	X	X	X
05	✓ (4)	✓	✓ (8)	✓	With local NHS trust	User group directory/database	Virtual – lay summaries
06	X	X	✓ (2)	X	With local NHS trust	X	Virtual – mock funding panel
07	X	X	X	With other NIHR	With local NHS trust	X	One/two join face-to-face mixed panel
08	✓ (7)	✓	✓ (6)	*X*	X	User group directory/database	One/two join face-to-face mixed panel
09	X	X	✓ (3)	*X*	X	X	Panel of lay representatives

In this model, the PPI team are involved only when greater expertise was required to provide ‘bespoke’ advice. This could be when PPI had posed more of a challenge, for example if the proposed project involved a complex design or methods, or hard to reach populations. This model generated a new element of general methodologist/specialist advisor training and keeping them abreast of new information.

> *‘Well here we’ve got our local advisors. And I feel that we work as a team and they come to me if they need a bit extra input or access to specific information or resources, and I see it as my role to keep people as up to date and informed as possible. Erm because I’ve got the time whereas they haven’t got the time.’ RDS-03 – PPI/A*

Only one informant described a different model where every client is referred to the PPI lead for their input. The primary reason for this was the lack of time in meetings with general methodologist and specialist advisors to adequately cover design, methods, and PPI.

> *‘The amount of time that we can devote within a (meeting) to the application for example, tends to be quite a lot and so we try and manoeuvre PPI out of there because otherwise you may easily take up a half-an-hour of the two-hour meeting.’ RDS-04 - PPI/GM*

RDS Website content review

Although the majority of RDS websites included an explanation of what PPI is, the available resources varied considerably, particularly direct access to PPI documents. Some relied largely upon links to specific INVOLVE webpages rather than directly to documents. Surprisingly some did not provide a link to the NIHR RDS ‘Patient and public involvement in health and social care: a handbook for researchers’.[286] Two of the eight had developed their own materials to support researchers with PPI. These included videos explaining what PPI is and writing a plain English summary, and documents such as top tips for PPI, guidance on the appropriate involvement of the public in panels and committees, in care home research and a glossary of research terms.

Training in PPI for researchers and RDS lay members

Training provision varied across the RDSs. A few offered PPI training workshops for researchers and one RDS ran these in conjunction with another NIHR organisation. One informant (RDS-02) said the demand for these had 'really dropped'. Some utilised PPI training – for both patients and researchers - offered by partner organisations, such as NHS Trusts, recognising these activities could be time-consuming and it was pointless to replicate when 'there are other people who are better placed to do it' (RDS-07). Another informant collaborated with a local trust to deliver PPI training to lay people and offered places on this training to their own lay panel members.

As the majority of RDS PPI advice was provided by the general and specialist advisors, most of the training was to ensure they provided the correct guidance to clients. This training was carried out as required and one informant mentioned PPI was often one of the refresher topics at staff away-days.

> *'We spend quite a lot of time making sure that all of the RDS advisors are clued up on PPI.' RDS-07 – PPI/A*

They also spent time ensuring general and specialist advisors were aware of PPI resources available within and outside of NIHR. This enabled them to signpost clients to further information such as what was available on the INVOLVE website.[98]

Access to patients and public

Researchers developing funding applications are expected to involve patients/public early in the process. Access to patients is often problematic[287] and the RDS has been cited as a source of support with this.[288] Three RDSs had a user group directory or database, containing details of NHS, community and charity groups across their region. Two of these sources were accessible from the RDS website for anyone to search for a disease specific patient group; the other was only accessible by the RDS PPI team. These directories/databases were clearly a valuable resource though one informant commented on the amount of time it had taken to develop and to ensure it is current. Keeping the databases up to date was a challenge because of the continual changes to these groups, with new ones being created and others disbanding.

One informant also signposted clients to the People in Research website[289] and invoDIRECT.[289] People in Research is a platform where researchers can register, provide details of their studies and the specific PPI they require, and advertise for patients/public to be involved. invoDIRECT is a directory of user groups across the UK that support PPI.

As PPI had become an established part of the research process there was an expectation from most informants that clients had their own patient groups, or access to one in their own institution, primarily NHS trusts but in some instances universities. Some considered there was less need for the RDS to be involved directly in identifying patient groups and it was not part of their role to do so.

> *'In terms of finding people for them, because it's an issue, it's not something that we can invest a lot of time into. And it is really for them to think about their actual project, thinking about diversity and their target population for that project and who is best placed to provide advice as well on the project. So it is something that we can signpost them to.' RDS-02 – PPI/A*

If clients did not have access to patient groups some RDSs directed them to other NIHRio, such as the CLAHRC (Collaborations for Leadership in Applied Health Research and Care) or BRCs (Biomedical Research Centres), although with the latter, patient groups could be disease-specific and may not be appropriate to involve.

> *'And then also what is a really good resource is the BRC because they have about twelve dedicated patient groups who meet regularly and researchers can come to them and present their findings so the researchers don't have to kind of get together their own bespoke group.*

> *But I mean yeah, it depends on the subject. But that covers quite a broad range of medical issues, actually.' RDS-04 – PPI/A*

Although there was an expectation that clients accessed patient groups out with the RDS, only two informants demonstrated an awareness of the existence of such groups available as a formal resource. They described a sizeable number of established PPI research groups based in trusts and universities. In one case, it was said most of the groups were not disease specific; their remit varied and not all contributed to the design of studies:

> *'Some of them are quite generic and they tend to like doing what I call tasks rather than like reviewing the plain English summary or organising a focus group.. But they are, yeah, they are erm well established, those groups.' RDS-09 – PPI/A*

The other mentioned the availability of disease-specific groups supported by a local NHS trust. The contact details of these (and other) groups were available from the PPI pages of the RDS website and open to anyone.

> *'A lot of researchers have benefitted from those panels. So members of the public are involved in right from pancreatic cancer right through to palliative care and those kind of things, mental health, erm various different panels that people can tap into.' RDS-08 – PPI/A*

Another informant reinforced the importance of utilising patient groups within trusts and RDS clients were signposted to the PPI lead there.

> *'All of the foundation trusts have registers of members, because it's a requirement of being a foundation trust, So it's one of my mainstays of advice, is "If you're struggling, go and talk to the trust PPI person and see if you can tap into the membership of the organisation where you're based", because I don't think we do that enough.' RDS-07 – PPI/A*

There were a few exceptions where the RDS PPI team were more actively involved particularly if the client was finding it difficult find patient groups. However, this was something informants considered they had little time for.

> *‘If it’s a rare condition disease and the client has made attempts and struggling, not quite sure where to go next, we’ll probably pro-actively say “Look, let’s get our heads together on this and see if we can find a group or is there a national group that we can tap into?” and we give them help with that. We won’t actually.., I mean, on occasion we have done match-making, where we are physically involved.’ RDS-06 - PPI/GM*

RDS patient and public groups

Five of the eight RDSs had their own ‘patient’ group who reviewed funding applications or the lay summary section of the application. Two of these were virtual panels of lay people. The focus of one was to ensure lay summaries were written in plain English rather than comment on whether the team had demonstrated ‘good’ PPI in their application; the other contributed as part of a virtual ‘mock’ funding panel as described below. The other three had one or two lay people join mixed panels of specialist advisors who met face to face. In some cases, the lay members were from a bank of people and their attendance at the panel was rotated. Most of these mixed panels mimicked the NIHR funding panels, particularly Research for Patient Benefit, and the lay members commented on the quality of PPI in the application. In contrast to the others, RDS North East had a consumer panel of patients and carers who met twice a month in two locations, the north and south of the region. In these meetings RDS clients presented their research and obtained feedback in a Q&A format. This group also conducted on-line reviews of plain English summaries.

The RDS North East struggled to attract new members, particularly those from underserved groups. Renewing the membership of the group was also a problem for another RDS as well as the sensitivity required in managing lay people.

> *‘We’ve had almost a year I think now, of trying to refresh membership, and to be honest we’ve been struggling, we haven’t got people banging our doors down, probably only got two or three people. . …….. we try and give them feedback of all the reviews they do and sometimes if they’ve actually misunderstood or got the wrong end of the stick or need some slight guidance with it, they won’t take that on board, and that’s when it’s quite difficult you know, “I am the patient here, I am right”, and that takes a bit of careful manoeuvring. It doesn’t often*

> *happen and as I say, their input and the detail that they go into is fantastic, it's weighing it up sometimes.' RDS-07 - PPI/GM*

Three RDSs had no specific PPI group. One informant reported researchers using the service accessed groups in their own institutes for this specific 'reviewer' type of PPI and there was little demand for an RDS group. The other two made use of groups in partner organisations, such as local NHS Trusts, universities and other parts of the NIHR infrastructure, for this type of PPI.

> *'So we tend to.., because most of the PPI groups only exist because of the enthusiasts within that unit, we tend to do anything through those units rather than have one directly attached to us.' RDS-06 - PPI/GM*

Patient and public involvement fund

All eight (nine including RDS North East) RDSs offered a small grant scheme. Its purpose was to fund early PPI to inform the development of a funding application.

> *'(it is) a fund for up to £300 that researchers when they come to the RDS, so if they say … "Right, I've got six people I want to ask about this study but I've got no money to pay for their transport to the hospital and to pay for them to have a little lunch after the meeting", we will say "Right, apply for some money through our … Fund, and we will help you pay for that", so it's a very popular award!' RDS-08 - PPI/GM*

This was a finite resource and in all but one RDS this was a competitive process and researchers applied for the funding. One informant considered the process of applying for this pre-application PPI money as an ideal opportunity to assess the research team's level of knowledge about PPI and their plans for meaningful involvement beyond that stage.

> *'So one of our … big jobs is looking at applications for (PPI Fund), and through that providing feedback and advice. So that has two roles, it's funding for people to have those meetings while they're putting the grant together. .…. we tend to iron out quite a lot of the PI issues … because then they have to make a case and talk about their PI … they're asked to make changes and there're questions asked, and that's quite a good process of actually the applicant learning about PI.' RDS-05 - PPI/GM*

Changing PPI landscape

The majority view was researchers, both clinical and academic, had a good understanding of, and appreciated the need for, PPI in research. Only one informant expressed the opinion that PPI was often tokenistic and an afterthought. Others reported they had noticed a change over time and RDS clients had an increased awareness of, and were more educated about, PPI. One informant commented it was rare to find a team who had not considered PPI or sought the input of patients. Another said clients were becoming more 'self-sufficient' particularly in finding their own patient groups to be involved in the design of their studies (RDS-03). This heightened awareness was observed when in direct contact with RDS clients and evidenced more widely by a drop in attendance at PPI training for researchers which was said to be 'a really good example of the changing needs of the research community.' (RDS-08).

This change in the research community was perceived by some to have resulted in a shift in clients' PPI requirements and had impacted on what the RDS provide. However, despite an increased awareness of PPI it was recognised there is still room for improvement in the practice of involving patients and the public which 'does not always go well' (RDS-05).

> *'People now don't need to know why to do public involvement, it's about how to do it well.' RDS-08 - PPI/GM*

5.3 Latent analysis to identify enablers and barriers to sharing and collaboration

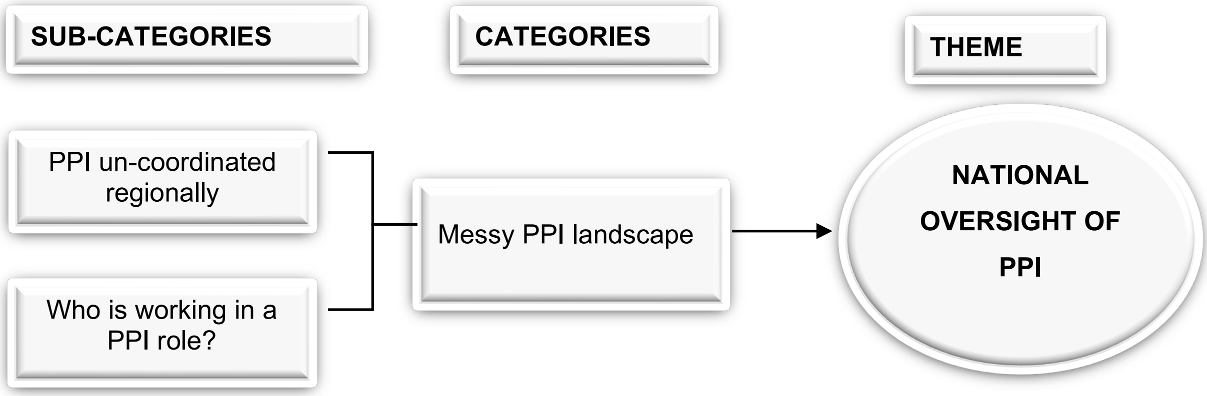
In the Going the Extra Mile review, Recommendation 7 'Connectivity' states the NIHRio should collaborate to develop regional PPI strategies and forums, identify and undertake cross-cutting PPI activities and build partnerships beyond NIHR.[79] With this in mind the barriers and enablers to PPI sharing and collaboration regionally were explored, and also nationally with other RDSs.

Three overarching themes were generated from the abstraction of codes, sub-categories and categories. These were: the ‘National oversight of PPI’, ‘Direction from NIHR nationally’, and ‘Create a collaborative culture’. These are outlined in Figure 5.3-1, Figure 5.3-2 and Figure 5.3-3 with the associated categories and sub-categories.

5.3.1 National oversight of PPI

The first theme highlights the importance of NIHR National oversight of PPI across its infrastructure organisations. The category and sub-categories abstracted to form this theme are based on informants’ views that the PPI landscape at a national and regional level is complex (Figure 5.3-1). Understanding the landscape, particularly the people and the practices, could facilitate PPI sharing and collaboration.

Figure 5.3-1 – Categories, sub-categories within the ‘National oversight of PPI’ theme



Messy PPI landscape

Who is working in a PPI role?

Although it was not a specific line of questioning, several informants raised the issue of the large number of people both nationally and regionally with a responsibility for PPI. One informant commented on the growth in the number of people in an NIHR

PPI role, albeit part-time. They believed the fact that many are part-time posts leads to a certain level of duplication of roles.

> *'Where you've got duplication .. you've got different people holding these what are probably part-time posts in effect, but there's so many of us. Simon Denegri commented on it as well at a meeting, it's just staggering. Somebody said we've generated a whole industry here, where's it going to end?.' RDS-01 - PPI/A*

There was also a lack of awareness of who has PPI remit or a dedicated PPI role both regionally and nationally. This would clearly impact on any efforts to share and collaborate across regions and, as the first informant pointed out, suggests the need for those with a PPI remit to be identified and begin to work together.

> *'I did a search of PPI officers in (part of region), there was something like 10, and of those, two people didn't even know they were PPI officers! So yeah, joined up thinking that's the way to go!' RDS-09 PPI/GM*
>
> *'I really think Going The Extra Mile and the review process, they've brought everyone together and it seemed ridiculous that they didn't know how many people were employed in PPI roles across the NIHR and they seemed to be shocked by it when they brought them all together. It is an industry isn't it?' RDS-02 PPI/A*

One informant had used the inaugural meeting of their regional PPI group to identify whether they were capturing the relevant individuals across their region. Similar to the experience of another informant in the earlier quotation they discovered individuals working regionally the RDS were not aware of.

PPI un-coordinated regionally

Most informants considered the regional PPI landscape was complex. They reported a general lack of awareness of the activities of others in a PPI role and a lack of coordination regionally.

> *'So (we are) trying to sort through the mud of what's going on.' RDS-09 PPI/GM*

> *‘I think people are doing different things.’ RDS-06 PPI/GM*

There were a number of motivating factors for co-ordinating PPI regionally. Duplication of PPI activities regionally was considered a waste of time and resources and of concern to several informants. Informants also wished to improve the quality of the PPI in their region. Suggested ways to improve quality were to standardise PPI practices to ensure all are conducted to a high standard and learn from each other. There was the belief that a more co-ordinated way of working regionally would address these issues.

> *‘There isn’t a cohesive PPI overview in NIHR, there are still bits of NIHR that do things very differently and not very helpfully either.’ RDS-04 PPI/A*
>
> *‘To avoid duplication, we’re trying from the RDS point of view to work with those partners as much as possible and deliver the service rather than…erm so for example, the engagement side of things, technically we’re not supposed to do that, but obviously you can’t involve without engaging, so the CRN, that is their remit. So we join up as much as possible from the public point of view.’ RDS-02 PPI/A*

Another rationale for a more co-ordinated way of working was a pragmatic one that could improve the service the RDS provided to clients in relation to PPI. For one informant, a greater awareness of regional PPI and activities would facilitate liaison with other PPI leads and enable their RDS clients to tap into patient groups under the auspices of other departments or organisations. This quotation illustrates some of the sensitivities around accessing patient groups.

> *‘There was concern about us stepping on other people’s toes …. (with greater awareness) we’d then be able to (access patient groups) a little bit more easily than if we were coming at it without any kind of insider knowledge.’ RDS-09 PPI/GM*

As demonstrated above, the motivations for co-ordinating PPI were primarily altruistic, e.g. wanting to improve the standard of PPI regionally. Only one informant talked about the potential benefit of cross-regional working for all individuals in a PPI role. They believed meeting up with others would enable people to support each other.

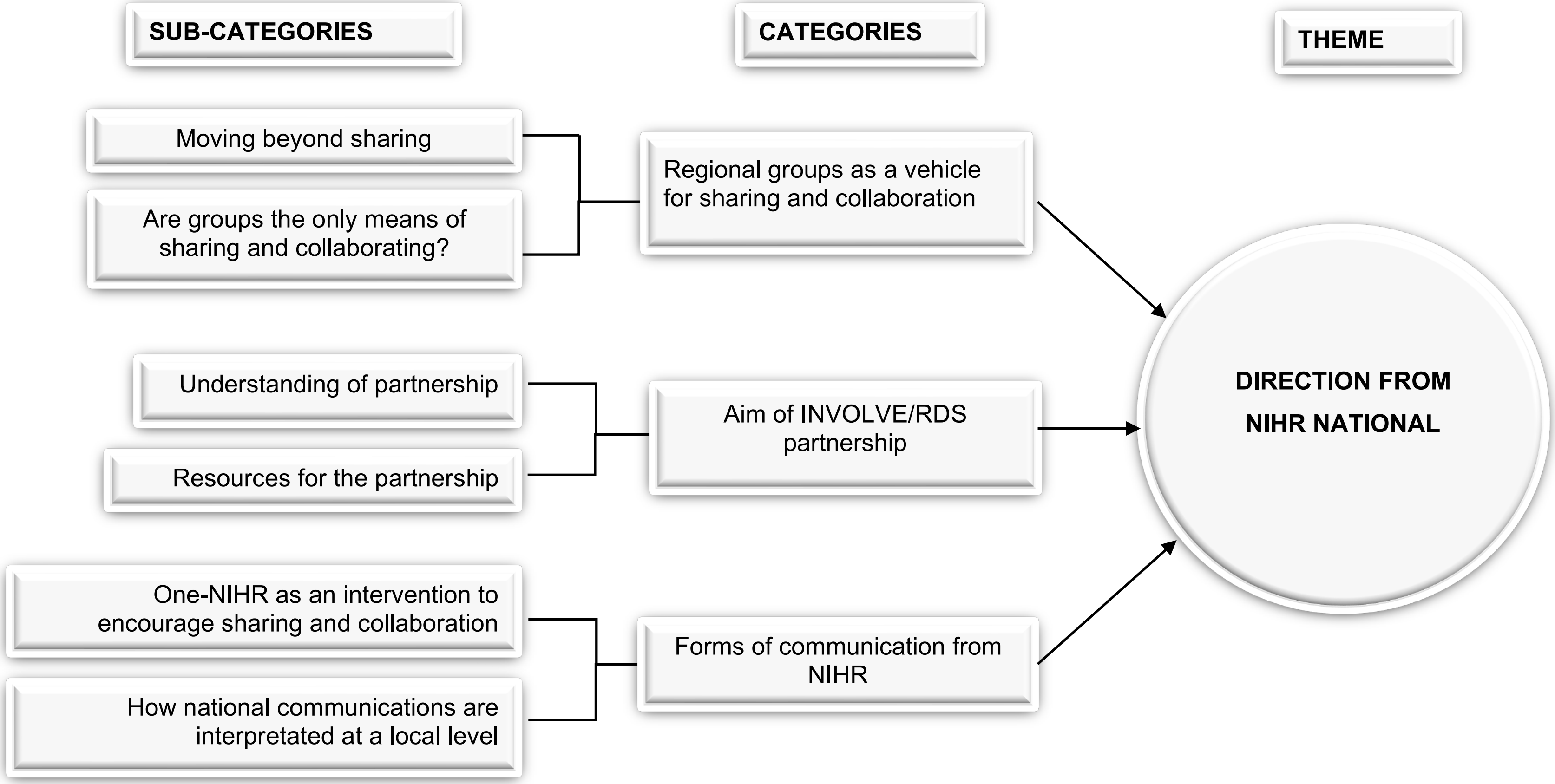
> *'Get us all round the table and see how we can support each other with delivering PPI within our patch.' RDS-01 PPI/A*

The increase in the number of NIHR PPI roles and the potential for duplication was of concern. At a local level, finding those in a PPI role was often serendipitous. Although some may be employed by NHS trusts for example, it is difficult to comprehend that NIHR PPI staff in each region could not be identified by NIHR national. Similarly, with national oversight of NIHR regional PPI staff activities it could be possible to demystify the landscapes. None of the informants discussed what the motivations to co-ordinate PPI might be for others in an NIHRio PPI role and what they could gain from it. This could impact on the level of engagement in endeavours to connect regional PPI.

5.3.2 Direction from NIHR nationally

This second overarching theme was generated by abstracting three categories: 'Regional groups as a vehicle for sharing and collaboration'; 'Aim of the INVOLVE/RDS Partnership' and 'Forms of communication from NIHR' (Figure 5.3-2). Although these are disparate categories, they all link to direction from NIHR National for those in an NIHR PPI role, both in the RDS and potentially in other NIHRio.

Figure 5.3-2 – Categories, sub-categories within the 'Direction from NIHR Nationally' theme



Regional groups as a vehicle for sharing and collaboration

One mode of co-ordinating PPI and gaining an understanding of the landscape could be through a regional PPI group who meet to share what they do and work together to identify opportunities and areas for collaboration. Six of the eight informants said they were members of, or were embarking on the formation of, a regional PPI Group. These groups included PPI staff from the NIHR and other organisations. Half of the regional groups mentioned had been in existence for a number of years.

> *'We have some really good networks in the area, other groups that we work with, … there's a group … which is almost like a co-operative if you like between the CLAHRC, the AHSN, the CRN and us, and we share PPI expertise and try not to re-invent the wheel really when it comes to doing training and that sort of thing.' RDS-05 PPI/A*

One informant said they had changed the remit of an existing group to encourage sharing and collaboration. The quotation demonstrates it can be a challenge to relinquish control and move to a model of shared ownership when the group has originally been initiated by a single NIHRio for their own purpose.

> *'We already had a regional group which my predecessor set up, but it … obviously had an RDS remit so it looked more at design. But it did involve most of those partners still. So what we've been trying to do is to evolve it and make it more collaborative and rebadge it, if you like, and erm so we're trying to let go of the ownership of it, which is hard.' RDS-07 PPI/A*

There was one newly established group, formed in response to the INVOLVE/RDS partnership which took effect from the summer of 2016. They had a strong steer from their RDS to meet with partners from other parts of the NIHR infrastructure in their region, as part of the partnership but were initially sceptical. However, the group met, and this had led to the formation of a breakaway sub-group to progress an agreed PPI initiative.

> *'I was asked to do it by my Director, we need to show willing, we've got to pilot this, and I actually thought "Ok, we'll do it, I don't think it's going to come to much, and then we can tick that box and say we've tried it" […] Actually it was a really good meeting, and a lot of interest in*

> *keeping the momentum going and meeting again within that bigger group … four groups, CRN, RDS, INVOLVE and AHSN helped with refreshments … At the beginning they thought of some co-operative, collaborative working, so that's good. RDS-03 PPI/A*

Another informant said they already had a strong network of NIHRio partners in one half of their region and, driven by the INVOLVE/RDS partnership, wished to replicate this in the other half. This and one other RDS were in the process of forming new regional PPI groups. These informants used terms such as 'attempting to' and 'trying to' when describing their experience, which suggests forming these groups is not without its problems.

In the remaining two RDSs without a formal process for meeting and sharing, linking regularly with all NIHRio PPI in the region did not appear to happen. One informant said they worked closely and effectively with a single NIHRio in their region and did not feel the need to collaborate beyond that. Despite admitting they were unaware of the PPI landscape regionally another informant was sceptical about the group model and wished to create a PPI community as an alternative. They added this was 'something I'm trying to do and not being very successful'.

> *‘‘(I'm) not really sure what's going on in the region which is the reason why it would be good to have some kind of community – that was a genuine community – so that we were in touch with each other and have better communication. .' RDS-08 PPI/GM*

Although a few informants talked about collaborative working, as demonstrated in the earlier quotations these regional groups appeared to focus mainly on sharing. Most of the groups mentioned earlier met quarterly though as stated in the following quotation the appetite seemed to be for one event each year again with a sharing focus.

> *'(the meeting) was really information sharing, what are we doing, what are we up to, what are our ways of working. Where we go next I'm not really sure. We opened it up and said "Do we want to meet again, what will be the purpose of the next meeting?" And people seemed to be keen to have maybe a yearly meeting to do that very thing, to update,*

> *not a conference but more of an information sharing. So we haven't actually got another project to focus on … But nothing else has emerged that everybody wants to put the time and effort into and work towards.' RDS-03 PPI/A*

Regional groups were considered an appropriate vehicle, for sharing at least, for some informants. Informants who were part of, and met with, an established group were less likely to comment on the confusing regional PPI landscape, and potentially had a greater awareness of what was happening locally with PPI. However, forming these groups is not always straightforward and not many had reached the point where they were collaborating with other NIHRio. In some regions, group meetings may not be the most efficient mode of encouraging collaboration.

Aim of INVOLVE/RDS partnership

The INVOLVE/RDS partnership came into force in the summer of 2016, at least a year prior to these interviews. To reiterate, the partnership was described in the INVOLVE Autumn 2016 newsletter as below.[284]

> 'Our new partnership with the Research Design Services is starting to take shape and through that partnership working we are now working collaboratively to support the development and co-ordination of effective regional patient and public involvement (PPI) networks which make best use of effort and resources increasing regional to local connectivity to extend and deepen PPI.' *(p1)* [284]

Most informants were aware of the partnership. As stated earlier, it was a driver for forming a regional PPI group for a few RDSs. Some others believed their existing regional PPI group met the partnership brief of co-ordinating effective regional PPI networks. Two informants who were relatively new in post had little knowledge of, or involvement in, the partnership despite the fact they were RDS PPI Leads.

Informants held INVOLVE as an organisation, and the team who worked there, in high regard. Their physical presence at regional meetings was considered important and thought to encourage others to attend.

> *'I think having INVOLVE round the table simply being able to say that and people want to come along […] But I think people are just keen to be updated with INVOLVE, have a face, .. talk to them personally rather than just maybe picking up the phone or going to the website.' RDS-03 PPI/A*

However, views about the direction and implementation of the RDS/INVOLVE partnership were mixed. Despite the partnership being active for over a year one informant commented it was too early in the process to predict the direction of travel.

> *'I think because it's still relatively new, … it's still got to establish a little bit, … So it's really hard to know what this new role has actually brought for us at the moment. [….] I think probably from a strategic point of view and from a visionary point of view, it's quite nice to have INVOLVE as partners with RDS … it seems like a natural thing that should happen, but in future work it will be interesting to see how it evolves really.' RDS-01 PPI/GM*

Picking up on the point that it is difficult to know what the partnership means for individual RDS, some informants were forthright and said the aims over the longer term were vague. Others, when asked about the partnership, merely talked about their regional group but nothing beyond that.

> *'I think as a whole, the RDS/INVOLVE contract is not moving forward as fast as I thought it might. … I think what's wanted is a bit woolly and that's definitely part of the problem.' RDS-05 PPI/A*

Another informant was doubtful the INVOLVE/RDS partnership would have any impact. They believed the whole venture, and PPI generally, is under-resourced and the key players are unable to devote the time to ensure it succeeds.

> *'We have a regional INVOLVE representative but, … I think they're quite stretched and although there are these quite grand ideas for partnership and what that will mean, I think on a day-to-day, … it feels quite under resourced and again … I just think people are very busy*

> *and therefore really building these kind of collaborations is quite challenging. RDS-08 PPI/GM*

The RDS securing this partnership with INVOLVE was considered a benefit though most were unsure of the direction this would take. It was unclear whether some informants thought an endpoint was establishing a network and did not envisage what was required beyond that. The fact that two RDS PPI Leads were not aware of the partnership suggests in some RDSs it may have had a lower priority. Greater clarity from NIHR, or possibly involvement of the RDS PPI staff in higher level discussions, about the partnership may have been beneficial to its progression and profile.

Forms of communication from NIHR national

As stated earlier it was decided to explore informants' interpretation of the One NIHR campaign launched in 2015, two years before the interviews were conducted. Simon Denegri described the campaign as aimed at 'building up a single identity for NIHR and giving those who work in it a sense of belonging'.[79] The main page on the website provided links to resources to enable staff to apply the NIHR identity. There were separate pages for NIHR staff, reviewers and public contributors that explained the role(s) and how individuals could promote NIHR.

The discussion about One NIHR was delayed until toward the end of the interview and two informants mentioned it spontaneously. One in relation to standardising the offer to clients across the RDS and the other to joint working.

> *'So I'm actually really pleased that now there's a lot more coordination and collaboration and we look at public involvement from the point of view of being One NIHR.' RDS-07 PPI/A*

All but one informant was aware of the campaign. Informants were asked what One NIHR meant to them and whether it had any impact on their role or on PPI provision. Most said that it was primarily a marketing campaign or strategy devised by the NIHR

Communications team, the aim of which was to present all parts of NIHR as one. The majority referred of the One NIHR logo and the ‘I am NIHR’ badge which one informant said was ‘physical proof that I am part of this family called the NIHR family’ (RDS-01). Others were more sceptical:

> *‘So my best bet was One NIHR was the badges, which I don’t want to wear. It’s really pretentious saying “I Am Research”, I’m not!’ RDS-02 PPI/GM*

One informant provided a rationale for the campaign that was accordant with the message from the relevant NIHR website at the time.

> *‘The NIHR is rather complex and we all have a remit to fulfil a different part of (the research) pathway. So from the public point of view we absolutely have to present a united front because otherwise … it’s just meaningless. … I think One NIHR helps us to think from the stakeholder perspective more.’ RDS-07 PPI/A*

Beyond the acknowledgement that One NIHR was a campaign or strategy for a unifying identity, some informants had a broader interpretation. These fell into three themes: increased collaboration across NIHR, better co-ordination of PPI, and standardisation of PPI provision. Responses to the concept of One NIHR as an intervention were similar across the informants and for most there was more than one response, some positive and some negative. Based on the view that One NIHR meant increased sharing and collaboration, one informant believed it would lead to more efficient working and ultimately save money. This would enable individual RDSs to use their PPI budgets more creatively.

> *‘I see (One NIHR) also from the point of view of resources, because we all have so little resources. At the end of the day the money comes from the one pot doesn’t it, the public pot?’ RDS-01 PPI/GM*

Although not a common response there was concern that, although One NIHR is a good idea in principle, staff have too little time to put it into practice. Others expressed confusion primarily about ‘how to’ implement One NIHR, considering there was little instruction locally or from the national team.

> *‘How it works and how we sort of work with it is quite confusing, actually, because I don’t really know whether there’s been anything set up. It seems really broad and there’s no … there’s not a lot of information.’ RDS-04 PPI/GM*

One informant talked about One NIHR in relation to the behaviour of other NIHRio. This was about PPI remit and the experience of NIHRio encroaching upon the RDS territory of PPI in the development of funding applications.

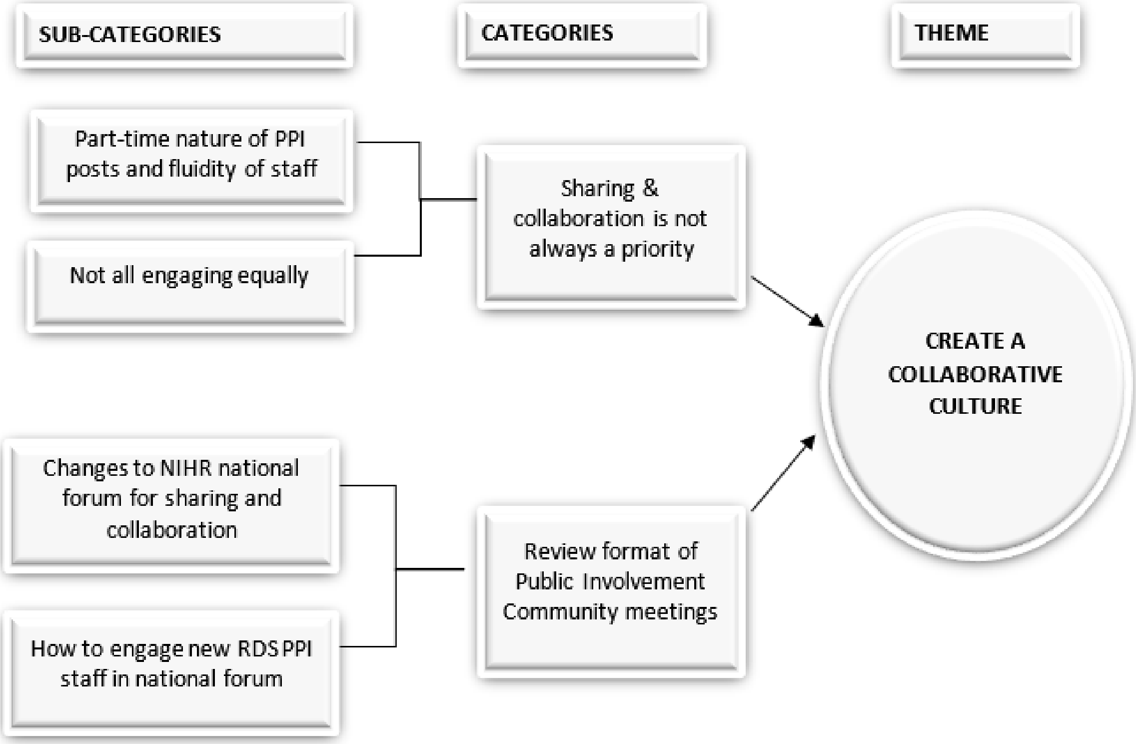
> *‘Sometimes it doesn’t feel like we are One NIHR, … and every time something happens that seems to go against the notion of One NIHR somebody will get out their badge and have a laugh about it, […] We did have a bit of a problem with (NIHRio), I don’t know if it’s a national thing but they seem to have changed their focus a bit … and based on putting on (initiative) that we don’t get invited to and it feels like “Oh my goodness!” you know “Where’s the One NIHR there?” One, we should be working together anyway, two, why are you doing (initiative) when that’s our remit?, and three, let’s do it together.’ RDS-03 PPI/A*

Most informants interpreted One NIHR beyond what was its original intention. This raises questions about NIHRs modes of communication and how what began as a campaign to encourage a unified identify could transform into something so different at a local level.

5.3.3 Create a collaborative culture

This theme was abstracted from two categories, ‘Sharing and collaboration is not always a priority’ and ‘Review format of NIHR Public Involvement Community meetings’ (Figure 5.3-3).

Figure 5.3-3 – Categories, sub-categories within the 'Create a collaborative culture' theme



Sharing and collaboration is not always a priority

As stated earlier, for most informants the goal of cross-regional working was to co-ordinate PPI to reduce duplication and/or improve the quality of PPI. To achieve this, and to gain an understanding of the PPI landscape, there was a need to engage as widely as possible with those in a PPI role in NIHRio and potentially other organisations. Most said they had achieved this, but a few informants expressed difficulties in engaging others from the NIHRio in the cross-regional group meeting model. This appeared to occur regardless of whether the group was new or well-established.

> *'If I'm honest we're not getting very good attendance from the (one NIHRio) even though they're supposed to be part of it, they're not really often there, … But yeah, I think that could be better if I'm honest. …, I'm sure it's stronger in other regions but I would say … in the past it's been good.' RDS-04 PPI/GM*

There was one other example of a lack of engagement from others within regional NIHRio. This was outside of the regional PPI groups as a forum for collaboration and sharing and related to an event that was meant to be planned and delivered collaboratively by regional NIHRio. In this example, the quality of collaboration and strength of relationships was truly tested in the run up to one of the International Clinical Trials days when a lack of engagement from some NHRio was cited as a problem. The CRNCC had asked NIHRio in several regions to work collaboratively to plan and conduct this event locally within a short timescale.

> *It's been very much myself and the AHSN and (one NIHRio) that have been getting … the venue booked, getting (the organiser) to come ,,, The (other NIHRio) have been very absent, if you like. But I'm sure that's probably because.., I don't know, I don't know, but I would say there isn't the sharing going on.' RDS-04 PPI/GM*

> *'I got this email out the blue saying we want you to put on an event … let us know by the end of the week, and then it transpired the CRN were doing it. But it was quite hard to find out who was actually going to be doing that in the (region), … think that's just an illustration of the lack of clarity.' RDS-06 PPI/GM*

As a lack of engagement was not cited as a problem by many informants, only a few commented on why this might occur. One informant was unable to shed any light on why one particular NIHRio in their region was reluctant to engage, but said some NIHR PPI staff are uncertain of their place in the research pathway, particularly when their remit is not at the design stage, and this may impact on engagement in cross NIHRio ventures.

> *'I see quite a few issues that come up, from people not really knowing what their role is once you get further downstream.' RDS-01 PPI/A*

Another informant thought it potentially due to minor issues such as the timing of the meetings. They also mentioned a certain amount of fluidity of staff in PPI roles which not only impacted on collaboration but also on scoping the regional NIHRio PPI landscape. Despite this they appeared to have succeeded in working collaboratively with most of the NIHRio regional partners. They emphasised the importance of relationships between staff in a PPI role. This familiarity was an enabler to cross-regional working.

> *‘Because a lot of the public involvement leads have been in post for quite a long time so we’ve had time to establish and get these sorts of lovely things in place.’ RDS-04 PPI/GM*

One informant who was not part of a regional PPI group thought a barrier to engaging in collaborations was the tendency for part-time PPI posts. This was problematic when seeking engagement particularly in regional group meetings. They added that communication across NIHR was poor and people in these NIHRio PPI roles did not mix. They said this was ‘a perennial problem’ (RDS-06) and summed up the difficulties in encouraging others to collaborate. This suggests the will to collaborate must come from individuals rather than be imposed by others.

> *‘I think it’s very hard to get people to link up and every way you think of doing it, it has to have a, any way you would force it, it breaks down.’ RDS-06 PPI/GM*

A lack of engagement from other NIHRio in their group meetings or shared ventures was an issue for only a few RDSs. The part-time nature of PPI posts was cited as a barrier. However, part-time posts are likely to be common across the regions, yet not all RDSs struggled to engage NIHRio PPI staff. This suggests sharing and collaboration is not a priority for everyone and there is a need to develop a collaborative culture across NIHR. The fluidity of staff in PPI roles and the lack of engagement suggests that sharing and collaboration should be formalised and become part of the PPI job description. This would mean that PPI staff leading regional group initiatives do not need to rely on existing or building relationships to encourage engagement.

Review format of NIHR Public Involvement Community meetings

The RDS has one formal regular national forum, the RDS Public Involvement Community (PIC). PPI Leads from each of the RDSs meet face-to-face quarterly with interim tele-meetings as required. This group could potentially provide the opportunity, as well as a platform, to share, collaborate and reduce duplication.

One beneficial outcome of the PIC group for the RDS PPI Leads was the identification of three areas of joint working. These were: to find solutions to challenges that affect all RDS PPI; to plan how to share across the RDSs, and to avoid duplication.

> *'It's a great platform to just be able to avoid duplication as well and share resources, so yeah, we're definitely in touch all the time and we have a JiscMail where we're able to share any ideas and things like that as well, so if there's anything happening locally we're able to do it through that as well.' RDS-03 PPI/GM*

The PIC appeared to be the sole vehicle for sharing ideas and collaborating across the RDSs. None of the informants mentioned any other informal contact in the interim with their counterparts. As the PIC was targeted at the PPI leads this meant that others within the RDS learned about the outcomes of each meeting from the attendees and/or the minutes.

Despite the PIC group being cited as a benefit and a good opportunity to work on PPI issues across the RDSs others had opposing views. In contrast to what was reported previously a few informants said, in their experience, the meetings were no longer a forum for sharing best practice which was a disappointment. It was suggested this was attributable to a change in the group leadership. This meeting had previously been led by staff from INVOLVE and changed to the PIC group in 2015, two years before the interviews were conducted.

> *'There's a few of us who felt that the way it happened, the directors were parachuted in at one stage, and it was done in quite a heavy-*

> *handed way, and we were told we weren't to be meeting informally again. It was just like we were being told a little bit like we were naughty schoolchildren, and a couple of the directors who have led it since have been process-orientated and not terribly supportive of sharing and best practice.' RDS-05 PPI/GM*

A few informants felt with this change of leadership there was a move to standardise PPI across the RDS and this took away the ability to be 'responsive and flexible to clients' (RDS-05). The meetings were said to now be more process-oriented and more formal.

> *'(previously) It was much more about sharing what we do, it was much more about "Oh I've got this client, I've come across this issue, has anybody done anything around that". … it's more strategy-focused now, it's more "Right, ok we're writing the tender now, the PPI section has to be written, what are we all putting in it?" You know, what similarities or what things should we put in that? It's got a different flavour now.' RDS-08 PPI/A*

Another issue was from informants who were new to the PIC group. Although it can be difficult to induct new members into established groups and ensure they can contribute, in the experience of informants, little effort was made to facilitate those new to the group. These informants found it difficult to follow the discussions at the meeting and one said they had struggled to get 'in the swing of it' (RDS-06).

> *'I found (virtual meetings) really difficult to get a hold on … it's like joining something mid-conversation. […] the all-day meeting was a bit better but still felt like an ongoing conversation that I hadn't kind of been part of. So still quite difficult to follow actually in some ways, and .., it wasn't really about erm sharing best practice in a way that I thought that was quite a shame.' RDS-09 PPI/A*

Informants' experiences of the PIC meetings differed considerably. It was difficult to know whether those who reported a positive experience had concerns about expressing negative views, or even acknowledging that the group had changed focus, as the PIC was led by RDS directors. Accepting that some no longer found the group to be a forum for sharing and collaborating and based on the experience of new members it suggests the PIC should review its format and try to create a more collaborative culture.

5.4 Summary

PPI provision in the RDS

The key points highlighted in this chapter are a change in the RDS PPI Lead role and the potential for sharing training and resources at a national level. RDS leads now train general methodologist/specialist advisors in basic PPI and keep them abreast of current PPI resources, signposting and guidance to new information. Although this makes sense it is difficult to conceive this training and updating would be an onerous or time-consuming task and questions whether RDS PPI time is being directed where it is needed. In most RDSs the dedicated PPI staff are involved when PPI is more of a challenge. However, with the passage of time examples of how others have successfully involved patients where it is perceived to be a challenge are emerging. This raises questions as to whether there will always be a need for this ‘bespoke’ PPI.

There are opportunities for sharing training in PPI for researchers and those in a lay representative role. Centralising information regarding PPI resources would enable RDS PPI staff to support those who consult the service. Establishing an NIHR database of patients/public interested in PPI (and those coming to the end of their involvement with a specific NIHRio) could alleviate the problem of regenerating RDS PPI groups.

Sharing and collaboration

The models of working as expressed by research informants were fairly uniform across the RDSs but the documentary resources available through the websites varied considerably. There was little evidence of sharing resources with other RDSs. Only one RDS website had guidance documents in their list of resources that had been developed by another RDS. This highlights a lost opportunity in sharing useful resources and that some RDSs offered much more on their website regarding PPI.

Three themes that impacted on sharing and collaboration were identified from the latent analysis of the interview data. The messy PPI landscape of un-coordinated PPI in some regions and not knowing who has a PPPI remit suggests the need for national oversight of PPI (Theme 1). However, this landscape also encompasses PPI in the NHS, universities and charitable organisations but beginning with the NIHRio would be a start.

The second theme of national direction from NIHR includes two linked categories of whether regional groups are the most appropriate vehicle for sharing and collaboration and the aim of the INVOLVE/RDS partnership. Some groups were formed or were thought to meet one of the INVOLVE/RDS partnership goals. However, group meetings were clearly resource intensive to form and difficult to move beyond sharing. There was a lack of clarity about the INVOLVE/RDS partnership, but it was unclear whether this impacted on the cross-regional groups. Greater direction from NIHR national on other ways to share and collaborate and on the longer term aims of the INVOLVE/RDS partnership could be beneficial to regional NIHRio PPI.

The final theme highlighted the need for a more collaborative culture. The lack of engagement from others in sharing and collaborative activities was attributed to the nature of NIHRio PPI but this was not an issue for all regions and could be that it is not a priority for some people. Building this into the role of NIHRio PPI would mean that when someone leaves a post their successor will continue with established sharing and collaborative activities and these are not reliant on relationships between PPI staff. The comments about the Public Involvement Community (PIC) were interesting, and it was cited as both an enabler and barrier to sharing and collaboration. It was difficult to understand how there could be such polar opposite views on its utility as a forum to share and collaborate. One explanation for negative views could be a reaction to the change in group facilitation from INVOLVE to RDS Directors and a more formal and top-down approach compared to previously. Based on the accounts of those who were not entirely happy with the PIC there is a need to review these meetings in order to make them a more collaborative and sharing experience. Interpretation of the One NIHR campaign message tended to be one of a joined-up way of working which is interesting considering the website makes no mention of this.

Chapter 6: Missed opportunities to harness skills and expertise? the views of NIHR funding panel public contributors

Funding panel public members are important in this multiple case study as they occupy the space in the research spectrum, between design and delivery, which determines project funding. The rationale for their inclusion in this project is to explore whether there is overlap in the role with PPI other parts of the NIHR infrastructure, and the potential to share and collaborate both across funding programmes and NIHR more widely. Exploring their role and involvement as funding panel public contributors elucidates PPI provision at the stage between research design and delivery and addresses the question 'What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHIR?'. Understanding PPI at this stage and public contributors' experiences in the role offers the opportunity to explore the second question, 'What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?'.

6.1 The case – public members of NIHR funding panels

The NIHR has 10 research funding programmes. Each have panel committees whose role is to critically review research project funding applications and meet to discuss which to reject, to invite to submit a full stage proposal or to award funding. The number of times panels meet, and the review processes are dependent upon the programme. Panels consist of methodological experts, those with expertise in a clinical area and/or funding remit (for example, those with experience of early phase trials for the Efficacy and Mechanism Evaluation Research programme) and public members (2-3 per panel). In addition, funding applications are sent for external review to clinical and methodological experts and when possible, members of the public with experience of the key health condition. In 2017/18 NIHR reported 383 public members reviewed 1060 funding applications and 143 members of the public sat on funding or advisory boards.[100]

The rationale for including members of the public in the funding review process is to ensure decisions also reflect the patient and public voice. Table 6.1-1 outlines the factors all funding panels consider when reviewing applications for project funding.[100]

Table 6.1-1 - How funding decisions are made

The funding boards consider questions like:

- Do the study outcomes matter to patients, families, NHS managers and decision-makers?
- Will the study lead to significant improvements in health or health services?
- Is there appropriate public involvement in the design and conduct of the study?
- Is the proposal methodologically and scientifically sound?
- Does the research team have the skills and experience to complete the project?
- Is the research good value for money?

From: National Institute for Health Research Annual Report 2014/15[290]

The specific funding programmes – Health Technology Assessment (HTA), Efficacy and Mechanism Evaluation (EME), Programme Grants for Applied Research (PGfAR) and Research for Patient Benefit (RfPB) - were selected as their panels are more likely to review applications with a trial design. Selecting these funding programmes provided a common thread, for example, informants would all be expected to assess PPI in trials and the potential shared training need. Other funding programmes, such as the Public Health Research Programme or Innovation for Invention, may attract more diverse study designs and the expectations for PPI may be different.

6.1.1 Documentation for public contributors

NIHR's Central Commissioning Facility (CCF) and Evaluation, Trials and Studies Coordinating Centre (NETSCC), who manage the four funding streams of interest, were asked if they would share the documentation linked to public panel members. CCF provided a 'Checklist' and 'Top Tips for public panel members' for the RfPB programme. The Checklist helps public contributors to identify the key factors within a funding application that are relevant to patient benefit. The Top Tips provides specific advice from other public panel members on preparing for and contributing to a funding panel meeting. A third document was obtained written for *lay external reviewers* for RfPB and PGfAR, with information on the task of reviewing and how to successfully complete a review. However, it later transpired in the interviews this was the document public panel members were given. The CCF engagement plan for 2016/18 was obtained independently. This provided some context regarding their policy for public contributors.[291] It states they will support their public contributors by providing 'telephone support, online resources for public contributors, task focused guidance documents, a welcome pack for panel members, 'buddies' for panel members, talks, workshops and working groups' (p4).[291]

There was some reluctance from the NETSCC team to share. One document was obtained for the EME programme but nothing for the HTA. No NETSCC policy documents for public contributors were publicly available. The EME programme document 'Guidance for Public Contributors on Boards', despite being rather short, does incorporate guidance on what to look for when reading funding applications and tips for a successful panel meeting. It also states public panel members' first point of contact for queries is the Senior Programme Manager and 'they are the person you will most get to know'. There is no mention of a buddy or mentor system beyond this.

6.2 Methods

In-depth telephone interviews were conducted using a broad topic guide, and data were analysed using qualitative content analysis (Chapter 3). The topic guide evolved over the course of the interviews as new topics emerged. For example, early in the data collection period informants discussed the use of external lay reviews in their own assessment of funding applications, this was added to the topic guide.

6.2.1 Identification and contact of public members

The process of identifying and contacting public members of funding panels described in detail in Chapter 3 Methodology. The chairs of the HTA, EME and RfPB (outside of the Yorkshire and North East region) funding programmes were contacted to ask if they would forward the request to their public panel members. The chairs forwarded the requests on to the PPI team at NETSCC who facilitated contact with public members for HTA and EME and the regional RfPB Programme Managers who identified five public panel members who were interested in being approached. The CCF was emailed for the PGfAR funding panels. They responded promptly and their PPI team contacted three public panel members.

6.3 Descriptive findings

Twelve NIHR funding panel public members were contacted between December 2016 and May 2017. Two of the RfPB public members were not interviewed as one asked for reimbursement for their time and the other agreed a time and date but did not provide a contact number despite emails to request one. The remaining ten took part in a single telephone interview.

Table 6.3-1 provides information on informants' training for the current panel and past experience of PPI. Three informants had been a public member of more than one NIHR funding panel. Others had experience of PPI in NIHR research schools and units, and in the larger charitable organisations. All had a professional background.

In the next two sections informants' experience of becoming a funding panel public contributor and how they approach the role are described. An in-depth (latent) analysis of the potential for sharing and collaborating is presented in Section 6.4.

Table 6.3-1 - Training and support for current panel and background information on informants

Funding Programme	Time on panel	Formal training	Buddy /mentor	Experience of PPI
Health Technology Assessment (HTA)	18 months	No	No	Research project panel, NIHR external lay reviewer for HTA
	3 years	Yes	Yes	NIHR panels/ groups, lay external reviewer, PPI for NIHR infrastructure organisation
	5 years	Yes	Yes	NIHR research prioritisation panel
Efficacy & Mechanistic Evaluation (EME)	1 year	No	No	PPI with charity, Lay co-applicant on funding application, NIHR external reviewer
Programme Grants for Applied Research (PGfAR)	2 years	No	Yes	Lay member guidelines committee, RfPB & HTA funding panels
	3 years	No	Yes	With Clinical Research Network, PPI for NIHR infrastructure organisation
	4 years	Not sure	No	On lay/consumer group for clinical body, RfPB Funding Panel, Lay co-applicant on funding application
Research for Patient Benefit (RfPB)	2 years	No	No	Panel member NHS Trust
	3 years	No	Yes	Lay representative NHS Trust, Lay external reviewer for PGfAR.
	1 month	Yes	Yes	Charity advisory panel

6.3.1 Becoming a funding panel public member

A few informants had been personally invited to join when PPI in funding panels was a novel initiative. However, as time has progressed it was acknowledged that recruiting public members has become a more competitive process. Most had applied after seeing an advertisement for the role of public member with their current panel, and then attended for an interview.

> *'When I started it was as much by invitation, an appointment, because it was a newish idea, now it should be as it is by public advertisement.' HTA-01*
>
> *'That one was face-to-face, and it was quite gruelling, the RfPB. You were given a topic that you had to present. I think because they are quite well paid there is a lot of competition now for patient and public involvement roles.' RfPB-01*

Informants discussed the type of person the programmes are seeking to recruit. They said the programmes need individuals who can cope with the board-type meeting and are confident to contribute to, but not dominate, the discussion. A few mentioned their own professional background may have been a factor in their selection as a public member.

> *‘They obviously select people who are not, you know, the quiet mouses in the corner by definition I think.’ RfPB-02*
>
> *‘I’ve been used to large Boards. So they’re looking for people who aren’t going to be overwhelmed by the situation or frankly of soapbox guys who just like the sound of their own voice and don’t know when to keep quiet so I guess, respect is shown but I think they try to select PPI members as the panel is a little bit more exacting than perhaps some other roles.’ EME-01*

6.3.2 Public panel member induction and training

Three elements of the induction process were identified: training, observing a funding panel and a buddy/mentor scheme. It was difficult to identify the order in which these were introduced as some of the informants had served on the panel for two or more years and could not remember. Not all informants received both formal training and a buddy/mentor for their current panel role (Table 6.3-1).

Formal training

Four of the 10 informants said they had attended formal training for their current role. The details and timing were sometimes vague. Training was said to have been held as either a half or full day, and for some on more than one occasion over the period of being a public panel member. From the informants’ descriptions the content of the training varied. The RfPB formal training was more comprehensive than for the other panels and had a practical element. The difference in the provision of training could be because informants from the RfPB panels had less PPI experience than those from the other programmes.

> *‘We were told “This is what we want to know from you, does (proposed project) seem important – it seems important to us as clinicians, does it seem important to you as a service user or a member of the public?”.’ HTA-01*

> *‘Well we had a session on the background, where does (PPI) come from, what are we doing, what are we trying to do? … Then we went through an example, and we’d already been sent that to read and we … discussed … what we thought, where did we come from, how do we feel about them, what were the issues. So really trying to get a feeling for what we.., we knew what we were looking for and how we felt about that.’ RfPB-02*

Five informants said they did not attend formal training for their current role, and one was unsure. The offer of training may have been dependent upon their PPI experience particularly if they had previous involvement in another NIHR funding panel. As former external lay reviewers for EME and HTA some informants had received training for that role. Because of this they had not had, nor did they expect to have, further formal training.

> *‘Having been an external reviewer when I was invited to the Board, I had a meeting, didn’t have any training as such, had a meeting where they told us, the roles and the guidelines and so on. ‘EME-01*

When asked in the interview if they would have liked to have received training, one informant said their preference would have been a one-to-one session. Group training would not have been beneficial to them personally they said because of the diverse backgrounds and levels of education of public panel members. They had received an RfPB panel member welcome pack, with information and guidance on the role of public members, which had been invaluable.

Observing panels

Most had observed a panel meeting as part of their induction, apart from two who were the first public members to join their panel. Some had received copies of the funding applications to be discussed at the panel to read through before attending to observe. Observation was beneficial, both for demystifying the panel meeting process, as well as being able to watch how the current public panel members operate.

> *‘At least you’re not surprised, you know what’s going to happen, you know what’s expected of you, because you watch the patient thing … and you go “Right, that’s what I want” and you watch … them do that and I went “Right, ok, I can see what they’re doing, that looks like a good plan, everybody seems to be happy with it and that’s what I’m going to do”. ‘ RfPB-02*

However, a few informants commented that every public member approaches the role differently. Although a minority view, one informant had previous experience of a public member whose behaviour they considered ‘embarrassing’ and others they felt were ‘nit-picking’ every PPI point. Because of this one informant questioned the benefit of shadowing another public contributor.

> *‘Even two PPI people can come to a slightly different opinion because they identify different concerns with the proposal and therefore come to a different opinion.’ PGfAR-01*

> *‘Shadowing again can be a bit something and nothing and it can affect how one person presents things and does things.’ RfPB-03*

Mentor/buddy scheme

Exploring informants’ views on the buddy or mentorship scheme was suggested by colleagues who served as funding panel (methodological) members. Unfortunately, any documentation about this scheme, particularly guidance for buddies/mentors, was not available from CCF or NETSCC. Informants used the terms ‘mentor’ and ‘buddy’ interchangeably and in certain cases appeared to mean different things. For example, both were used to describe the other public member whom they ‘shadow’ and someone from a different funding panel who could be contacted by telephone or email for advice.

Five of the ten informants had a mentor or buddy as part of their induction. These were other panel members, usually but not exclusively another public member. There were mixed views about the benefits. One reported the scheme of great value and a key part of the learning process, whereas another thought undertaking the panel member role was more useful. These different perspectives could be due to the level of experience as panel members, as the former was new to NIHR and the latter had previously served on an RfPB panel.

One informant expected their mentor to provide a ‘critique’ (particularly of written reports) which would facilitate learning to be a good public member. This did not happen, possibly as the programme reinforced that panel members are considered equals rather than “I am your teacher and will tell you”. (JC HTA 5 years).

> *‘I had a mentor so I thought “Ooh good”, so I sent him my first report and said “What do you think of this?” And he replied by sending me his and saying “What do you think of mine?” What I wanted him to say was “Don’t say that because it’s not actually the sort of thing you ought to be saying”, “emphasise that”, but I’ve never had that.’ HTA-01*

Of those who did not have a buddy/mentor for their current panel role, one person had experience of a mentor in a previous PPI funding panel role for a charity. They thought a mentor may have been of benefit when they took on their current panel membership with PGfAR.

There were differences *within* some funding panels in who had a buddy/mentor that could not be explained by length of service. RfPB panels are regional, and this could explain the differences, but it is not clear why in a national panel such as the HTA some panel members would be offered a buddy/mentor and others would not.

6.3.3 The role of funding panel public member

Informants described their current panel role involved reading both first stage (outline/expression of interest) and second stage applications. The exception was the EME funding panel, where public members review only the second/full stage application. In this panel, public members do not contribute to panel discussions at the outline stage but when a proposal progresses to the second stage, they are encouraged to look at the outline/expression of interest applications. For PGfAR the public member provides written comments on the first stage outside of a meeting and then the second stage in the panel meeting.

Depending on the panel, they may have to prepare a report, complete a proforma or make notes to present at the meeting. Informants reported that at second/full stage they also have sight of the external reviewer comments. These were also useful to provide a more rounded view of the application.

> *So I then make other notes based on (own initial comments and the reviews of others), that I'm then going to actually take with me to the meeting. And those that go through from stage 1 to stage 2, I get those back as stage 2's so that I can then have a look and see, you know, how have these evolved from stage 1? Has any notice been taken of the comments that were made?'. RfPB-03*

> *'I find as much information as you can get, really useful, really useful and I'd always want to read what anybody says about it just to kind of fill in some blanks'. PGfAR-02*

Informants were asked what they focus upon when they review funding applications. As might be expected, this was guided by the structure of the documentation that formed part of the review, but some had specific aspects they believed important. These fell into two categories, the first related to the research question/trial design and the second to the PPI. For the research question some informants focused specifically on whether it is addressing a problem of importance to both the NHS and to patients themselves. Based on the information provided they make a judgement on the scale of the problem, the potential impact of the research findings and the difference it might make to patients in the longer term. Informants also considered the design of the proposed study particularly the feasibility of it being delivered in an NHS setting and from a patient perspective, and whether the team can recruit to the study.

As might be expected, the degree and quality of PPI in the preparation of the funding application was also assessed, whether it is a 'bolt-on' and tick box exercise, 'proper integration rather than involvement' (EME-01) and how the application has changed in light of PPI. The description of PPI for the duration of the study was also assessed particularly who they intend to involve and how they will be supported in the proposed activities.

The final aspect of the funding application public panel members said they focus upon is the lay co-applicant. One informant said it was a concern when there was no PPI co-applicant, and it was unclear who would be supporting PPI and ensuring the patient view is being considered. When there was a lay co-applicant, informants assessed how involved they were in study development and the application. One informant reviewed the number of lay co-applicants.

> *'It's a danger in having one person because a PPI co-applicant is only representing their narrow experience and unless they're representing lots of other people with conditions or that they're locked-in in a very successful way to community networks … they could have a very distorted view. […] So I think not just having one approach, having a couple of different approaches to PPI makes it better.' RfPB-01*

Several informants were sympathetic towards the applicants and understood the difficulties of involving patients based on their own experience. These tended to be informants who had been directly involved in the development of funding applications, and/or funded studies.

> *'How are they going to recruit them and select them when they've made contact? it's hard enough to get lay people anyway and in a sense you can't start being picky when people have volunteered to this, you can't actually say "I'm terribly sorry I don't think you're bright enough to cope with this!" […] I was a co-applicant on a study and I helped set up a patient panel, and it really was a case of when these people come along and say "I'd really like to help", you can't say "I know you're not going to be able to cope with this".' PGfAR-03*

6.4 Latent analysis to identify opportunities for sharing and collaboration

Three overarching key themes were abstracted from the public panel member informant data: 'Revision of public contributor training and support', 'Cross NIHR PPI

Exchange' and 'Complementary PPI'. Each theme is presented in a diagram with categories and sub-categories (where relevant) and discussed with illustrative quotations in the following sub-sections under the category headings.

6.4.1 Revision of public contributor training and support

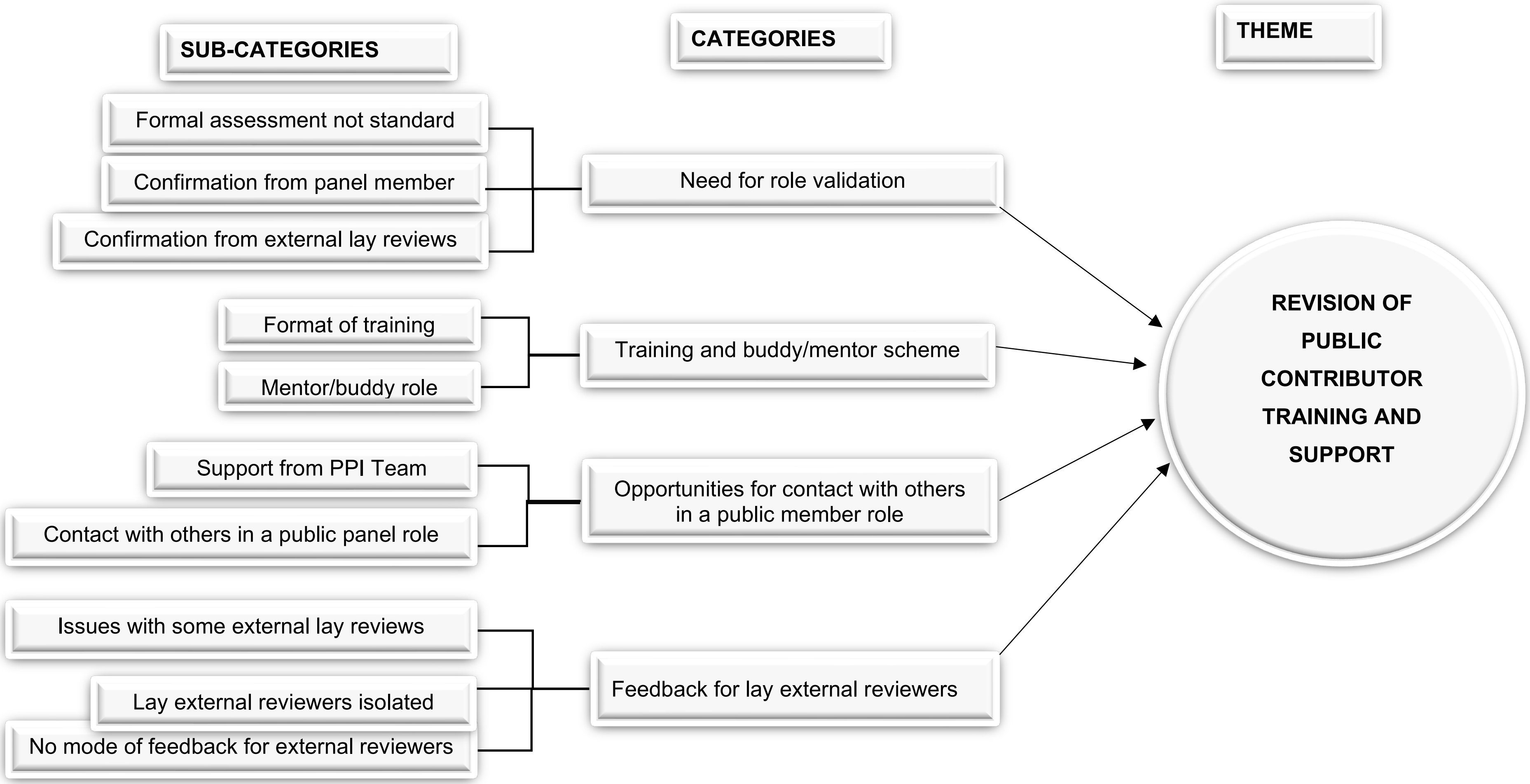
This theme was derived from four categories: 'Need for role validation', 'Training and buddy/mentor scheme' 'Opportunities for contact with others in a public member role' and 'Feedback for lay external reviewers'. Figure 6.4-1 outlines the categories and sub-categories which are discussed in the following sections.

Need for role validation

For most informants there did not appear to be a formal system for public members of panels to obtain feedback on whether they were fulfilling the role to a sufficiently high standard. The absence of evaluation and feedback on performance, or appropriateness of input, could mean that occasionally bad practices were observed in funding panels as mentioned earlier. In fact, only one informant mentioned a formal process of obtaining feedback on their performance. It was unclear whether this was a new initiative as this came from an informant who was relatively new to the panel or if this assessment varies depending on the region where it is based.

> *'You are assessed at the end of the first year by the Chair and assuming you don't keep falling asleep or arguing with the Chairman, you go up to two years, end of two years you are assessed again and you can be asked for a second two years and then you step down. RfPB-02*

Figure 6.4-1 – Categories, sub-categories within the 'Revision of public contributor training and support' theme



Informants were keen to prove their worth to the panel and demonstrate they were a valuable addition particularly, as a number commented, considering the high calibre of their fellow funding panel members. Because of this some informants were, or had been, anxious about speaking in front of the group. There were concerns about saying something foolish in the panel meetings and examples of having done so. Another informant although not fazed by the environment was initially anxious about their own contribution.

> *'I've had a lot of Board experience before I joined so … I'm just completely used to that environment. Having said that, when I first joined I was daunted, not by the people or the Board dynamics but just thinking, what can I actually add, because.., what do I know that's worth saying?' HTA-02*

It could take some time to gain some self-assurance particularly, as one informant commented, as the opportunities to make a good impression are limited due to the fact the funding panel meetings are infrequent.

> *'I mean it took a good .. I would think it took a good 12 months to feel confident that I was doing a good job.' HTA-03*

> *'You don't want to waste their time or look a fool […] we meet twice a year and at the end of the day you're only going to go to 8 meetings so you're going to make it pay […] because you've got to hit the ground running, it's no use turning up and thinking "Ooh well I'll just sit and watch what's going on". RfPB-02*

Gaining assurance that they were undertaking the public member role to a satisfactory standard was difficult and as one informant said, 'I suspect I'm like every other PPI person, I have no idea if I'm really useful.' (PGfAR-02). Perhaps because there was no formal or regular mode of receiving feedback, different modes of validation of their role, or of their contribution, was a common thread across the interviews, even the longer serving members. Validation could be in a form of feedback from a buddy/mentor or other panel member. One informant commented that how the other panel members respond was a gauge as to whether they were fulfilling their role as public member.

> *‘I hand over to somebody this summer and I shall say “Well this is what I do” but in a sense it’s validated by the way it’s treated at the meeting and it’s not validated by somebody sitting down with you and saying, you know, “If you did this it would be better still”.‘ HTA-01*

Another form of validation was the way in which informants used the external reviews, particularly the lay reviews, in their evaluation of funding applications. This provided confirmation that their own review of applications was in accordance with others. The value of being able to do this was recognised when the process changed for one funding panel and external reviews were no longer sought at a particular stage.

> *‘‘When you read an application then you would read the reviews and think “Oh yes I was right about that” or not. But now it’s completely down to your own judgement. And then you have to score it, again without any knowledge of what anybody else is doing.’ RfPB-01*

Training and buddy/mentor scheme

This category was elicited from the descriptive data reported earlier where it was clear there was a lack of standardisation across and within the funding streams represented in this work in the offer of training and support. The ethos of PPI is to consult and involve lay representatives and, because of the levels of experience and different needs of the informants, asking public members what they would like from training and a buddy/mentor scheme is key.

Opportunities for contact with others in a public member role

Informants were asked if they received sufficient support in their public member funding panel role. The response from most was they could always telephone the funding programme team. However, this tended to be for technical issues and problems with the on-line system. Informants were positive about the support from the PPI teams at NETSCC and CCF though one thought there could be more interaction between the public members and these teams.

Beyond the programme team and the initial training session with new public members – for those who had experienced this - very few informants had any contact with those in a similar role to their own serving on other funding panels.

> *'The only other time you may come across another PPI member apart from those on your panel, you and the other person, is if you are then seconded to another panel meeting.'* PGfAR-02

Informants were asked if they thought meeting with public members of other funding panels on an on-going basis would be of any benefit. Views were mixed as to whether they would find this useful. One informant had attended one ad hoc meeting of public members and thought convening the same on an annual basis would be beneficial.

> *'They basically took all the funding streams within the CCF and invited the lay members, so there were about, I suppose a dozen of us meeting, also with the Chairman, to discuss, how PPI was going, and that was useful. [..] But yes I would say an annual meeting of all the people involved on the lay side would be very useful.' PGfAR-01*

Although not all informants felt it necessary, some said they would welcome a regular meeting with others in a public member role, if there was a purpose for doing so.

Feedback for external reviewers

As demonstrated in Section 6.3.2 the provision of public member panel training was not standard across, or within, funding streams based on the informants' accounts. Some had received training as lay external reviewers and the RfPB guidance document obtained was directed primarily to reviewers. External reviewer training was not explicitly explored but the interviews highlighted the quality and usefulness of the external reviews, particularly the lay reviews. Although informants were mainly positive about the input of external public reviewers, most had some experience of reading reviews they believed were lacking in different ways or just generally bad.

> *'Over my time I've seen some public reviews that I've just thought "Oh that's a really bad review" RfPB-01*

As lay reviews provided additional information in the decision-making process and were used by public members to verify their own assessment of an application, the quality and pertinence of these reviews was important. When informants disagreed with the lay external reviews, bearing in mind all funding panel members have been privy to these, public members had to report this to the panel with a justification for their own viewpoint.

> *'In my report I say "The reviewers have been positive, they said this and this, but the PPI reviewer was condemnatory but I believe that we shouldn't…, for these reasons I don't believe we should take his view as the one we follow. And that only happens sometimes but you did say "Do you ever?" and the answer is yes, sometimes you feel the PPI has gone off-target, has gone off-beam.' HTA-01*

Two key issues characteristic of poor lay external reviews were highlighted. The first was related to the length and depth of the lay external reviews. Whilst short responses from external lay reviewers were said to be of little use, at the other end of the scale those that go off topic and provide lengthy responses were said to be equally unhelpful.

> *'What you want from a lay review is pertinent and snappy but when it goes on for pages about what they had for breakfast and how that makes an impact on.., I suppose you ignore it, just the same way as you do if it's the other end. And that is sad because sometimes people have some useful things to say but …you end up with something which you don't feel you can rely on as judgement.' PGfAR-02*

The second point raised was the focus and scope of the review. Although not a common experience, a few informants described external lay reviews where the person appeared to have their own agenda which influenced their opinion of the proposed project. Another informant suggested some lay reviewers are unrealistic in their expectations of PPI within the application.

> *‘We do get one or two people … who almost write a book, they go far beyond their brief, and condemn something for not having enough PPI when at that stage it wasn’t appropriate. Some … see themselves as experts in the PPI field and want more than can be reasonably expected at the time, and sometimes …the PPI person has got an axe to grind, … So sometimes I do disagree with them.’ HTA-01*

This focus of external lay reviews perceived by informants to be sometimes off-target raises questions as to whether the most appropriate people are conducting these. It was not possible to obtain information on how external lay reviewers are identified and recruited, and whether there is a specific person specification. However, in the CCF (which manages RfPB and PGfAR funding programmes) strategy document they describe a project underway at the time called ‘Reviewer Match’. In this project they were collecting information from public reviewers in order to ‘match their experiences with research topics in individual funding applications’ (p9) and to identify gaps in the experience in their current pool and inform the recruitment of new reviewers.[291] Therefore, the assumption is, wherever possible, external lay reviewers will be approached to review an application when they have the key condition. This was a challenge for the funding programme team.

> *Sometimes it’s a patient with experience of the condition but other times it’s.., if they haven’t got anybody, because, there’s an awful lot of conditions and not many lay people, then it’s a member of the public with a more general view.’ PGfAR-03*

Even when the funding programme team have been able to match a funding application with a lay external reviewer with the key condition, a few informants stated these can be problematic as the reviewer is too expert, too close to the issue or their experience is not in accordance with current clinical care.

> *‘Recently there was one where the lay reviewer gave a very low score and everybody else gave a high score. But it turned out that in that instance the person was drawing on personal experience which meant that they weren’t completely up to date with the clinical thinking and for once they were just wrong.’ HTA-02*

In defence of external reviewers and in relation to the length and depth of reviews one person thought time pressures on *all* external reviewers played a part in how comprehensive the reviews are (PGfAR-02). In addition, those informants who had been, or were currently, lay external reviewers expressed the view that the role is not always easy. They do not have the support of the wider funding panel, as public members do, and receive no feedback as to whether they have produced a good or bad review.

> *'Whilst the applicants get the feedback from the Board, the external reviewers don't. So there's a closed feedback loop for the external reviewers, because they might be giving really duff advice and never find out in the extreme.' EME-01*

The need to provide feedback to external lay reviewers was also raised in relation to reviews informants believed were unreasonable particularly toward the research applicants. Ultimately it was thought these types of reviews could be counterproductive in the endeavour to encourage researchers to involve patients/public in research design and conduct. It was argued that a system should be implemented to address the issue of what were perceived to be unfair or biased reviews directly with the reviewer.

> *Some people … are kind of barrack room lawyers … and some of those are lay people and … I had one which was almost offensive in the tone it took about the study which actually I thought was rather a good study, but had really taken against it for some reason and was really quite rude, and I thought "This is simply not on, somebody ought to be monitoring this and taking a sample of everybody's reviews and saying 'you need to be careful about tone'". … And I thought "If I were an applicant reading this I would really hate lay people from that person onwards!".' PGfAR-03*

6.4.2 Cross NIHR PPI exchange

The Cross NIHR PPI exchange theme incorporates the potential opportunities for public members and for NIHR PPI more widely. These opportunities could be beneficial to public members in fulfilling their panel role and, for those at the end of their term, go on to be involved in other PPI initiatives. Other parts of NIHR could benefit from the wealth of experience and expertise panel members have attained during their service. This theme was created from three categories, ‘Continuity of PPI role’, ‘Harnessing experience and expertise’ and ‘Knowledge Exchange’. Figure 6.4-2 illustrates the sub-categories and categories that form this theme.

Continuity of PPI Role

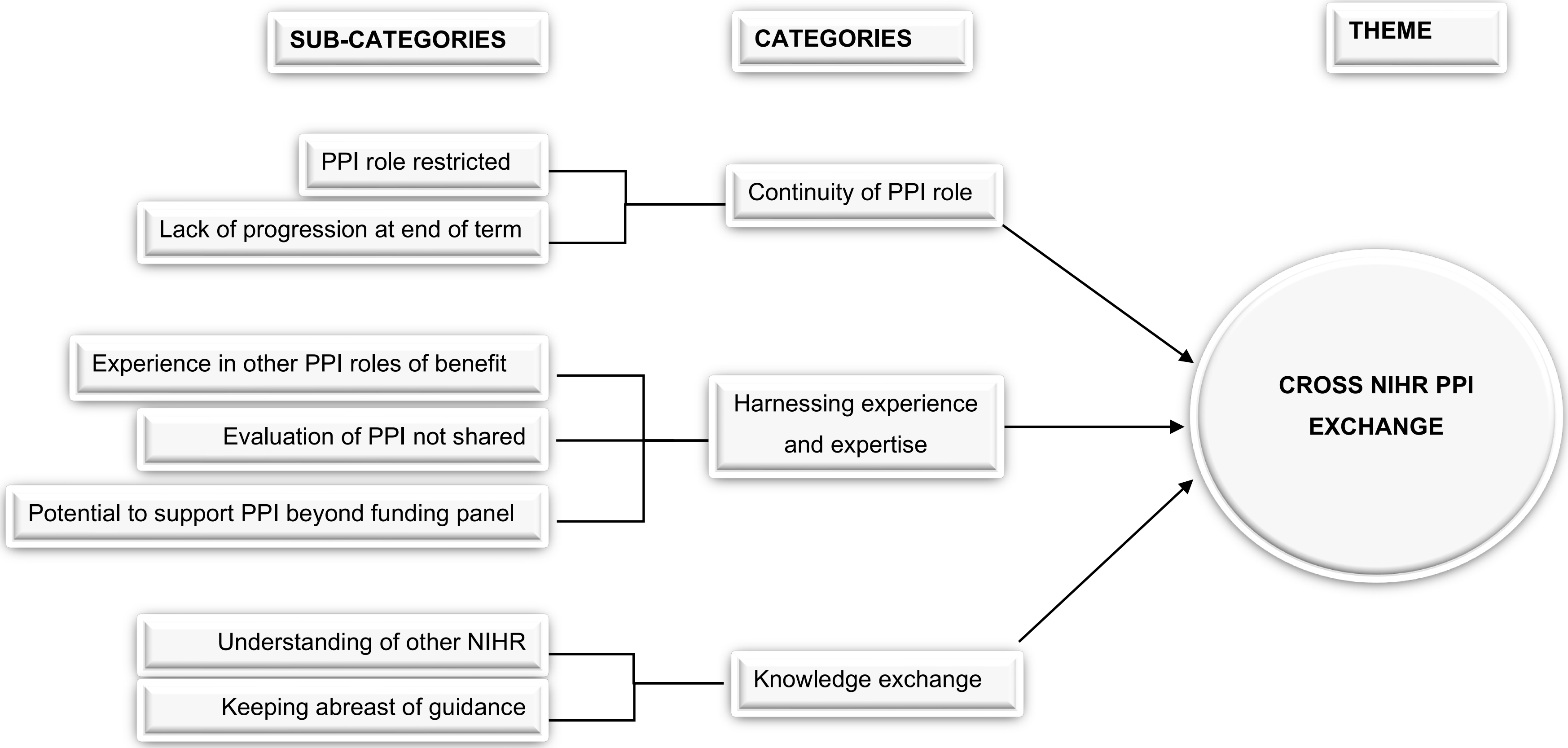
As demonstrated in Table 6.3-1 most informants had a wealth of PPI experience both from their time with NIHR and other organisations. How this experience was utilised by the NIHR funding programme teams was explored in terms of continuity of the PPI role either as a funding panel member or in another capacity. As stated earlier, most informants had been recruited to the funding panel after they responded to an advertisement and attended for interview. However, a few informants already in a PPI role within NIHR or a linked organisation were approached directly by the funding programme.

> *‘I think they got in touch with me and then one thing led to another so I probably had interviews moving from one panel to another but I was already in the system rather than applying from outside.’ HTA-02*

Only one informant had crossed between CCF and NETSCC, and served on the HTA, RfPB and PGfAR panels. This was attributable to a longstanding connection with a senior clinician who had some involvement with the different funding boards. Approaching public members who are coming to the end of their service to join another panel could be a prudent way to capture and retain those with the relevant experience. However, there was no evidence of this happening to informants serving on panels overseen by CCF.

> *JL: ‘So when (RfPB) ended, were you approached about the Programme Grants?’*
>
> *Inf: ‘No I applied myself.’ PGfAR-03*

Figure 6.4-2 – Categories, sub-categories within the ‘Cross NIHR PPI Exchange’ theme



Regarding extending the length of time public members serve on a panel informants generally thought it important to adhere to the guidance and aim to have a regular turnover of public panel members. One informant, who had been critical of research teams whose lay co-applicant was someone regularly called upon for PPI and is ‘on 46 steering groups’, thought it correct to limit the length of time public members serve on panels.

> *‘And again that’s so important that you’re getting turnover, it’s not the same people year in, year out […] you can’t do more than four years, and I think that’s excellent.’ RfPB-02*

Some informants were nearing the end of their term serving as a public member. When asked if they were continuing in a PPI role within NIHR one informant said:

> *Inf: ‘Well I’m not a young person (laughs), although I’m still interested. [..] but the answer is I don’t know. I would expect them to think it was time I was pensioned off!’*
>
> *JL: ‘It, seems a shame when you have all of that experience and expertise.’*
>
> *Inf: ‘Well it is, it is but when I started it was as much by invitation, an appointment, because it was a newish idea, now it should be as it is by public advertisement and therefore it ought to go to a wider range of people rather than keep on the originals. I mean I would like to be kept on but I can see a good reason why not.’ HTA-01*

Another informant commented on the restrictions their funding programme imposed on the number of PPI roles public members can undertake. Once they had joined the funding panel, they no longer received applications in a lay external reviewer capacity. They thought this was unfortunate considering the difficulties the funding programmes have recruiting suitable public contributors and ultimately should be the choice of the individual.

> ‘They always say that they’re looking for more patient reps and so on, so I don’t think it’s a case of finding jobs for everybody on their database. Certainly the EME Board is quite a high workload […] So they do it to limit workload, but that’s their choice, not mine*. If a PPI rep*

> *is willing, and able, there's no reason why they can't wear multiple hats.' EME-01*

Only one informant mentioned their current panel involvement leading to other activities within NIHR, namely the recruitment of new public members for funding panels. Another said they would like to contribute to the training of subsequent public members of funding panels.

Although there may be some benefit in recruiting different public members after a certain period, it could be considered a missed opportunity to lose someone with several years' experience. Even if there are no opportunities on other funding panels it is hard to imagine that this experience and expertise could not be put to good use either in panel training or another part of the NIHR infrastructure.

Harnessing experience and expertise

There could be opportunities to draw upon and utilise the experience and expertise of public members in the wider NIHR. This category was generated from the sub-categories relating to the importance of wider PPI experience, that the extensive review of PPI is not shared with applicants and the potential for such experienced individuals to have role in supporting PPI beyond funding panels.

Experience of other PPI roles of benefit

PPI experience beyond the funding panel was important and beneficial. Informants with more experience, either as a panel member or beyond that role, provided greater detail when asked about their specific focus when assessing a funding application. In addition, when describing this assessment these informants could draw upon examples of where particular models of PPI had and had not worked well. Informants who had experience of PPI in different stages of the research spectrum also had an increased awareness of the issues faced by researchers when involving patients/public in the development of funding applications and were more grounded in their expectations of PPI. One informant also talked about the sheer amount of work involved in developing a funding application.

> *'I am a co-applicant on a Programme Grant … so I've seen it from both sides, which is I think really useful because every single application I read I am so aware of how much work someone would have put in, in preparation for this.' PGfAR-02*

Evaluation of PPI not shared

When discussing what is fed back to the applicants particularly when the PPI is flawed, most thought this would be 'headline' information only such as 'PPI needs strengthening' (HTA-01). Despite both panel public members and lay external reviewers evaluating the PPI, providing detailed feedback on how it could be improved was not considered appropriate. This appeared to be a decision on the part of the funding programme.

> *'It's not very detailed but it might say … "Go to the Research Design Service, go to INVOLVE", but yeah, they definitely do have an ethos which is, "We're not going to tell you how to do it, we're going to tell you it's got to be better", but it's only a certain amount of hand-holding.' HTA-02*

One of these informants went on to say some applicants need more guidance. They stated that despite the growth in the number of applicants who understand PPI and can demonstrate patient/public contribution to the development of the project and their continued involvement, there are others who struggle.

> *'You often see ones where it's another hurdle in the application, so some clear guidance about, what to do and when, and with who, and where to find those people and how long their involvement continues and that sort of thing.' HTA-01*

Potential to support PPI beyond funding panel

As illustrated earlier, some informants highlighted the difficulties for research teams not only in identifying patients/public to involve but also recruiting the right type of person. The difficulties for patients/public involved in a lay capacity for the duration of a project were also discussed. One example given was ensuring lay representatives on projects can fully contribute in a steering panel meeting. During this discussion one informant identified an additional role public members of funding panels could fulfil, in supporting patients/public who were contemplating lay involvement in research projects.

> *JL:* *Sometimes clinicians I work with really struggle …, the people they know will be good don't want to take it on because they maybe feel intimidated … so I think it's quite tricky.'*
>
> *Inf* *Yeah, but the intimidation should be addressable, I mean, or at least you could have a small panel of people in it, like myself, who could just talk to people who are considering it and allay any fears that they have, and put their mind at rest.' EME-01*

Knowledge exchange

The potential for a more joined up way of working, particularly a two-way exchange of information was identified. This category was generated from a need for greater understanding of other parts of NIHR and to keep abreast of current PPI thinking and guidance.

Understanding of other NIHRio

Although several informants had experience of PPI in a project or in other NIHRio there was a lack of awareness of the wider PPI NIHR landscape. Some informants were curious about PPI at the research design stage. Two informants asked why PPI was inadequate in applications that stated the team had consulted the RDS. They were surprised to hear that some applicants say they have consulted the RDS when they have not and there was no sign-off from the service. Although a relatively minor issue, this seemed important for panel members to know, particularly those new to the role whose assessment of the application may be influenced by them believing the RDS were involved.

> *Inf:* *'Occasionally, we get applications with very poor PPI and they say they've been through RDS…And one thinks to oneself,*

> *"Hang on, did RDS approve this or did they say something to the researchers who chose to ignore it?" and you're never quite sure which it is.*
>
> *JL: We're reliant on the applicant to send that to us, people can submit and say that they've used the RDS when they haven't, there's no cross-check.*
>
> *Inf: That explains such a lot!' PGfAR-03*

Another informant wished to gain a greater understanding of how the lay co-applicant role is integrated and complements that of the others named on the funding application. Having the opportunity to work with a research team as a lay co-applicant may have helped to demystify this process and help this informant in their assessment of PPI in the applications.

> *'I would have liked to have understood more about the process of the application and the different roles and the different expertise and how the lay role fitted in with that. They try very hard to do it but it's one of those things that's very nebulous.' RfPB-03*

Keeping abreast of guidance

The importance of having experience of different PPI roles was highlighted earlier, particularly as a co-applicant on a funding application. However, another informant with experience of developing a PGfAR application applied a model of PPI, suitable in the context of a large programme of work, to RfPB applications which are a much smaller concern. For example, in their assessment of RfPB applications one informant used the number of lay applicants as a criterion of good PPI. This stemmed from their experience of being one of several lay co-applicants on a PGfAR application where they were struck by the diversity of views between them.

> *'But me and the other PPI co-applicants had very different views. So that's why it's a danger in having one person because a PPI co-applicant is only representing their narrow experience.' RfPB-01*

This could be a training issue but also highlights that panel members may gain some insight from being involved in the development of a funding application for the funding stream they serve on. Remaining on the point of lay applicants, public members' focus on this as a PPI quality indicator which is at odds with the intelligence cascaded to other parts of the NIHR. At that time the guidance given to the RDS was that lay co-applicants are not always necessary.

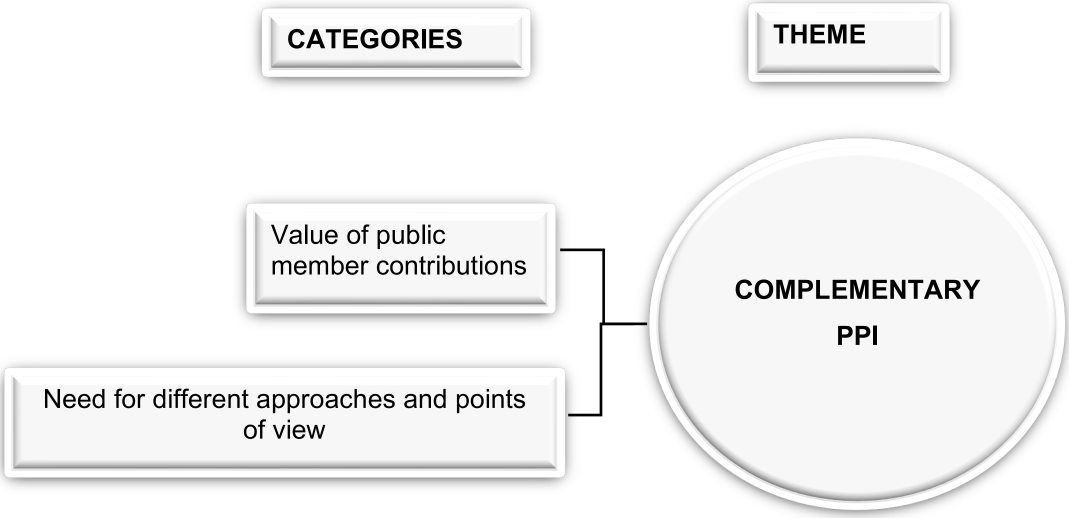
There were other examples that on the surface appear minor but suggest a disconnect between funding panels and the research world. One informant expressed frustration that they had not heard the results of a study the panel had recommended for funding. They did not appreciate the time-lag studies experience, for example, due to managing contractual issues between NIHR and the researcher's organisation.

> *'It's two years down the line now and a lot of these studies were two years, what is coming back? It would be lovely to have three bullet points for each study coming back as to what the outcomes have been. Has the hypothesis been proved or disproved? You know, what has been changed as a result, because if that's not happening, what is the value in all the money being spent?' RfPB-03*

6.4.3 Complementary PPI

The Complementary PPI theme relates to whether, as time progresses and researchers become aux fait with PPI, public contributors are required and whether PPI could be streamlined to reduce duplication of activities, for example having both public members and external lay reviewers assess PPI in applications. Two categories fed into this theme: the value of public member contributions and the need for different approaches and viewpoints (Figure 6.4-3).

Figure 6.4-3 – Categories, sub-categories within the ‘Complementary PPI’ theme



Value of public member contributions

The informants acknowledged that the research landscape has changed, and PPI is now more widely accepted in research planning, development, conduct and dissemination. Some informants said that the methodological and clinical panel members often commented on the quality of the PPI in the meetings and in their written reports. However, it was perceived that this acceptance is progressing more slowly amongst the wider research community.

> *‘This has changed over the years, I don’t feel people nowadays on the funding panels need to be convinced that PPI has to be in there. I think there’s a big difference between those who are on funding panels who are already understanding the new way of the world, and some researchers who are still dinosaurs. But again, it’s still changing and there aren’t that many researchers around who are dinosaurs.’ PGfAR-02*

Considering this change informants were asked whether, now or at some point in the future, funding panels may not need a public member to assess PPI. Some were unsure and others argued the lay perspective in research funding decision-making was of value and should be maintained. One response was that we have not yet reached a point where research teams understand what good PPI is, and informants argued they continue to see funding applications where it is very poor. The issue of applicants stating they have consulted the RDS but may not have taken their advice on board was mentioned again. Until there was a process in which PPI in funding applications could be assessed as satisfactory prior to submission, it was thought that its evaluation by public panel members was required.

> *'If there was a way of the RDS kind of endorsing (PPI), then maybe not, I mean that would add potentially another layer into it and as the lay people are already on the panel, I can't see the point in saying "Well, there will be some that don't need lays".' PGfAR-02*

A second point was informants believed they brought a unique perspective to the panel, either directly from their own experience or as a non-clinical/methodological member. They felt able to put themselves in the shoes of prospective trial participants sometimes drawing upon their own experience as a patient. By taking the patient's perspective they identified issues non-public panel members may overlook. The same informant also pointed out that the presence of public members at the meeting 'stimulated all of the Board members to be thinking about PPI'. (HTA-02)

> *'I usually come second or third (in presenting their view during the panel discussion) but people listen because on the whole, they'll get an everyday response rather that the decimal point should be in a different place, that kind of technical response.' HTA-01*

Finally, one informant suggested as the research should be of benefit to patients it is only natural that patients/public should be involved at the point at which a decision is made on what should be funded.

> *JL: 'Do you ever think we'll reach a stage where research teams will understand PPI and there'll be no need to review it?'*
>
> *Inf: 'I don't know is the answer, and to be quite honest, in real time, why would you not involve patients? That would be my question, why wouldn't you involve.., if you're doing research to benefit patients, why wouldn't you involve patients?' RfPB-02*

Public members considered themselves the arbiters of PPI, as the methodological and clinical panel members are for other aspects of the funding applications. They also argued public members are key to the discussion and without them PPI would have to be evaluated by others.

> *And also, I suppose the other thing to come back to is, and I suppose this makes me sound like a bigot, but actually I'm there on the panel to read those lay reviews, just as everybody else has access to those lay reviews, but to give people my own judgement with an indication of where that judgement came from. PGfAR-02*

Need for different approaches and points of view

The issue of the need for both lay external reviews and public member reviews was discussed. Most argued that both are needed. The reason was, as mentioned earlier, different people will identify different issues, and this is the rationale for having extra input to assess PPI. Informants thought their own assessment of the application insufficient as they are only providing one perspective.

> *So I suppose you have to bear in mind that I don't feel I am… I only have my own experience, I wouldn't class myself as.., I'm an expert in my own experience but it's only one viewpoint. RfPB-01*

The lay external reviewer role was considered to be a 'different job' (HTA02) and complementary to the public panel role. Relying solely on external lay reviews would result in a biased opinion as the reviewers have not been privy to the discussion or the views of others.

> *'The external reviewer is doing this as a one-off on his own, or her own, each time. They have no idea what anybody else gives, what scores. And if they like the proposal and they think it's a good area they'll score it highly, without necessarily always looking for the snags.' HTA-01-*

6.5 Summary

In summary, the interviews highlighted several important points. The first relates to training and support. Although it was unfortunate that few could remember the training they had and that the programmes were not forthcoming in sharing documentation, there was potential to revise training to better meet the needs of public contributors. When first embarking on these interviews it was expected that generic training in reviewing applications and attending panel meetings would be offered, yet there appeared to be inconsistencies across, and within, the different funding streams. Not everyone was offered the opportunity to have a mentor and some of those who had one questioned their value. The funding programmes should discuss with public members what they need from a mentor or buddy. Training may also reduce the need for validation at least in their review of PPI in funding applications and a process of providing useful feedback as to whether they are fulfilling the public member role would be beneficial. Although not everyone was interested in meeting with public members from other panels this could be a good opportunity for others particularly those who were new. The isolated situation of external reviewers was highlighted and the need for a process of feeding back about good reviews and those that were too long/short or had lost focus. As public members also review the application, giving external reviewers sight of these could be helpful.

A cross NIHR PPI exchange could be of great benefit. There did not appear to be a clear pathway of progression to other funding panels or other parts of the NIHR and this seemed to be a lost opportunity. The informants had a wealth of experience and expertise that could be useful to others in the NIHIR or in NIHR funded projects. With regard to the public member panel role, it was difficult to understand why the public contributor reviews could not be provided, in their complete form, to applicants when the PPI was sub-standard.

Conversely, they could benefit from the opportunity to experience involvement in other parts of NIHR. The informants who had experience of PPI as a co-applicant or as a lay member of a research project appeared to have more grounded expectations of what was feasible, and the difficulties research teams encounter in trying to involve patients.

The opportunity to engage with other parts of the NIHR in a PPI exchange initiative would give public members a greater awareness of the research development process. The focus of always including a lay co-applicant appeared to be at odds with the intelligence cascaded to other parts of the NIHR at that time. It seems key that advice given to those applying for funding should be also given to those judging the applications.

Finally, funding panel public members considered their input and expertise as different and complementary to those conducting the external lay reviews. They highlighted the differences between public members and lay external reviewers and believed their own role was one of giving a final judgement on PPI based on their own and the external review.

Chapter 7: Operationalising PPI in research delivery? the views of Local Clinical Research Network staff

Patient and public involvement for the duration of a project - at the research delivery stage - is crucial. However, if there has been no, or suboptimal, PPI, involving patients/public at this stage may lead to, for example, amendments and resubmission of ethics documentation and further review by committees if changes to the study design and conduct are recommended. The local Clinical Research Networks promote PPI and have dedicated individuals or teams with a PPI remit. Understanding PPI provision and how it is operationalised at this third point on the research spectrum addresses the question ‘What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHIR?’. As with the RDS, the local networks have counterparts nationally and other NIHR infrastructure organisations regionally with a remit for PPI and exploring their experiences in the role will contribute to the second question ‘What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?’.

7.1 The case – local Clinical Research Networks

The Clinical Research Network (CRN) was created in 2006 to tackle the decline of clinical research in the UK and provide the infrastructure to enable the timely conduct of research. Its role was to support the delivery of research in the NHS. In 2007 the CRN consisted of seven topic specific networks, each with separate geographical presences, and 25 Comprehensive Local Research Networks (CLRN) added to cover other health conditions. The extent of PPI support provided varied, but in the topic networks it encompassed a range of stages in the research process. In April 2014 the 102 research networks, eight co-ordinating centres and central co-ordinating centre were merged into 15 local CRNs (locCRN) and one national coordinating centre (Chapter 1). In the summer of 2015 Jonathan Sheffield, the CRN CEO , reported the ‘core business of delivering research remains unchanged’ but now had ‘a very clear research delivery model’.[90]

7.1.1 Identification and recruitment of case informants

Staff from the 15 locCRNs with a PPI role were the informants of interest. In October 2015 Chief Operating Officers (COOs) and PPI Leads (where named on the website) were contacted by email to explain the purpose of the study and ask who to approach to interview (See Chapter 3 Methodology).

Originally one data collection time-point was planned. However, early into data collection it was clear PPI was in a state of uncertainty due to the transition (merging of networks). Obtaining a ‘snapshot ‘of current PPI provision would not be as straightforward as expected. It was decided to continue to interview staff from the remaining locCRNs and conduct follow-up (Stage 2) interviews 16-18 months later to allow time for PPI to embed into the new structure.

7.1.2 Data collection

A broad topic guide was used (Appendix I) which evolved over the course of the interviews. The Stage 2 topic guide included the core areas of exploration but was individualised to recap on any interesting issues from the first interview (Appendix J).

7.2 Descriptive findings of PPIE provision in the local CRN

7.2.1 Informants

At Stage 1, 15 COOs were contacted by email and 13 responded. After two weeks, follow-up emails were sent to the non-responders. Of the 13 who responded, two offered to be interviewed and 11 forwarded the request on to someone they believed appropriate to participate. Twelve interviews were conducted with an appropriate PPI contact, from 12 of the 15 local CRNs. Most interviews were conducted in October/November 2015 with two delayed until April 2016.

Twelve Stage 2 interviews were conducted in spring 2017, approximately 16 months following the first stage. Seven of the 12 Stage 1 informants participated in a follow-up interview. The remaining five had left the network and interviews were conducted with three individuals who had taken on the PPI role. In the locCRNs where the two PPI staff had not been replaced, another person offered to be interviewed; and in the other there was said to be no one available to speak about PPI. The name of the new PPI lead was found for one of the Stage 1 non-responders, and when contacted they agreed to an interview. Including Stages 1 and 2, data were collected about PPI provision in 13 of the 15 locCRNs and the total number of unique informants was 17. Six informants were new in post and eleven had been with the network before the 2014 transition.

7.2.2 Informant roles

The roles of informants within the locCRN varied (Table 7.2-1). Seven informants designated as PPI Leads/Managers/Officers and Network Facilitator had a PPI role exclusively. This entailed supporting PPI by providing advice, resources and training to locCRN staff and 30 speciality groups, and six divisions and promoting PPI to the public. For the rest PPI was additional to their main role. Research Delivery Managers are responsible for managing the delivery of locCRN portfolio studies within each of the six research divisions, developing and implementing the division strategy, ensuring performance targets and strategic objectives are met, and leading a cross-cutting network function. The remainder were COOs and Deputy COOs which are executive roles within the locCRNs. COOs are responsible for the operational management of the locCRN including senior leadership and oversight within NHS partner organisations, supporting the development of the locCRN strategy and planning with the Clinical Director. Deputy COOs support the COOs in these activities.

Managing PPI alongside another locCRN role could be problematic: one person described PPI as ‘a full-time job’; the lack of capacity to do more was a source of frustration. For some this was temporary until they filled the PPI post.

Table 7.2-1 - Stage 1 & 2 - informants' roles

locCRN	Stage 1 interview	Stage 2 interview
1	COO/PPI Lead	Deputy COO
2	COO	PPI Lead
3	PPI Lead	No one available for interview
4	PPI Lead	PPI Lead
5	Network facilitator	COO
6	PPI Lead	PPI Lead
7	Research Delivery Manager	Research Delivery Manager
8	Deputy COO	Deputy COO
9	Deputy COO	Deputy COO
10	PPI Manager	PPI Manager
11	PPI Lead	PPI Lead
12	PPI Officer	PPI Officer
13	Email forwarded to PPI person - no response	No one interviewed
14	No response from locCRN	PPI Lead
15	No response from locCRN	No one interviewed

The quotations in this chapter are labelled with a number, the stage (1 or 2) the interview was conducted, and informant grade - senior management (SM) or manager (M). As before different informant numbers have been used in each new sub-section.

7.2.3 Team composition

PPI team size varied across the locCRNs. Seven were working alone and all but two of these had plans for new staff posts (often a combined PPI/Communications role). Four were working with one other person and one had a team of five staff responsible for PPI.

Three locCRNs had a vacant PPI (or PPI/Comms) post at the first interview. By the time of the second, two had recruited to the post but in one the person had left; the third had encountered delays in recruiting and the post remained vacant. Three others had lost members of their PPI team between Stage 1 and 2 interviews. Two had no plans to recruit to the original post and were thinking differently about PPI and links with partner organisations.

> *'We're probably not going to re-appoint because they're embedding us in the NHS organisation. So it will be me as strategic lead, with admin support and we're working with the comms so it's Communications and*

> *PPIE, we've got a Communications lead and then we're going to work with the NHS organisations because actually that's where we think it sits naturally in terms of communications and members of the public.' 01/S2/SM*

7.2.4 Context

The transition was an important contextual feature of the locCRN case to highlight and explore with informants. Managing the transition was of significance particularly regarding the potential for collaboration and sharing across NIHRio.

Those in post before the transition (specifically in topic networks) described PPI in the development and design of research as very strong and 'mature'. Other PPI ranged from setting research priorities to plugging the PPI gaps in funded studies supported by locCRN. The PPI models and practices had evolved over five years and most of the previous topic networks and CLRNs had PPI patient groups (PG) in some shape or form. These groups were no longer relevant post-transition, unless their focus was research delivery. When asked what happened to the PPI PG one interviewee said, 'a lot of groups went by the wayside'.

> *'The reasons why these groups were running were perhaps not as robust in terms of delivery as they should have been. But of course before that they didn't have to be, you see. So that was the issue. So I think that caused an awful lot of upset, really a lot.' 02/S1/SM*

When planning for the transition some locCRNs had not budgeted for PGs. There had been unrest among the PPI community about the changes and concern about the impact on PPI if researchers had to pay for a venue and refreshments for meetings with PGs. One informant talked about the 'delicate balance' in managing PPI during transition to ensure the good practices and established groups continued in other settings (03). However, there was uncertainty around how to access these groups.

> *'(Had) to encourage people that they didn't need to stop what they were doing, it's just the support for those structures might come from elsewhere … that was difficult for people to accept what had gone in the past was no longer there but a new structure had come up and*

> *some chose or felt that they couldn't go on ... It certainly wasn't a message from the network, but undoubtedly there was lots of funding that went into different areas that we weren't able to continue as the new network went forward. 03/S1/SM*

> *'The topics were diabetes or mental health and … you …, had a clear understanding of how to get PPI in your study now it's a bit more.. these groups are not around so where do you go? And I think it's the RDS for me, I think they're really got to try and develop.., that's their remit isn't it really?…02/S1/SM*

The wisdom of relinquishing established PG was questioned. A few said the rationale of the CRNCC was that not all the PG were needed and could be accessed through charities. Some considered this latter point idealistic and not all charities can, or will, help. One informant commented if this was the plan then work with charities pre-transition, to explore opportunities and to pave the way for sharing, would have been useful.

> *'The answers back were "We don't need all these groups because, you're just going to go to the charities and they'll give us PPI feedback", well they don't, you see. if that was the assumption then perhaps we should have got all the charities together to say, "How can we do this?" but if you think about it that's a massive bit of work, isn't it. So not a good time, not a good time.' 02/S1/SM*

The focus on research delivery also had implications for locCRN PPI. Informants admitted others had asked 'What is the point of PPI in the CRN?' and there was some scepticism about the effectiveness of PPI in research delivery when studies were already funded and had gone through research ethics. locCRN study portfolios are large and evaluating PPI or seeking patient involvement in those where it is lacking was just not feasible. This delivery focused work was described by some as 'new' and as a 'different angle on PPI'.

> *'When it comes to study delivery there's not much scope or not a big area that PPI can make a difference from the study delivery point of view. […] 'What we're looking at is at the moment, even nationally, is about training, is about the patient experience, it's all at the other end of the scale.' 04/S1/M*

Some admitted there was a blurring between PPI in research design and delivery and continued to support PPI activities at an earlier stage. One informant believed restricting locCRN PPI staff to research delivery was unnecessary and unrealistic, particularly for those who had a PPI role in other settings.

> ***Inf**: I like to link in with researchers, so I'm trying to train them to do it much earlier with me, when studies are in the pipeline, so we can talk about how we can involve patients very very early on. So that's something I'm developing.*
>
> ***JL:** So what would that involvement entail, is it about design or is it about the delivery?*
>
> ***Inf:** Well em.., we are the delivery arm of the CRN so although I know how to point people in the right direction, I wouldn't be targeting people too early on, just for me to help deliver the study really. Having said that, it's really difficult to separate that, I find that quite troublesome.' 02/S1/SM*

> *'There are always some people who take things literally and even though there were those people who were saying "Oh we're just about delivery, we can't do anything else" I've never said that, <u>never</u> because it's not a reality for most people who are experienced in working in PPI, they're involved at lots of different levels and it makes sense for that to be the case.' 05/S2/M*

Others very clearly made their focus delivery. They acknowledged that others across the NIHR and partner organisations provide PPI in other stages of the research process and the locCRN role was to signpost people to that support.

> *'So picking this up really with the new network it was very much about shifting the emphasis from the network's point of view that other work is all still going on but essentially sits in other parts of the NIHR infrastructure. So trying to refocus our emphasis from the network point of view around PPI input into the delivery agenda. And em so we've done quite a lot of that but it has come as something new.' 06/S1/SM*

7.3 PPIE provision in locCRNs

The transition took place in 2014 and it was not until April 2015 that a key stakeholder strategy working group began to develop a five year engagement strategy - The Patient Public Involvement and Engagement Strategy (PPI&E Strategy).[292] The strategy is aligned to the NIHR report 'Promoting a Research Active Nation'[293] and the recommendations of the 'Going the Extra Mile' review.[79] It describes a 'current' state of a 'fragmented and poorly coordinated approach to PPIE in research delivery' (p19) and outlines the five-year goals to actively involve and engage patients, carers and the public in the effective delivery of research. The Annual Strategy Implementation Plan is reproduced in the appendix (Appendix N). Table 7.3-1 outlines the aims, objectives and activities from the PPIE Strategy document relevant to this project. Some of these initiatives are locCRN PPI metrics. The activities are described in more detail in the subsequent sub-sections.

Table 7.3-1 – locCRN aims, objectives and activities from the PPIE Strategy

Aim	Objective	Activity/Initiatives
Improving recruitment to studies – short and long term	Improve access to information about trials	Lay testing of trust websites
	Raise awareness of research	Events to raise awareness/showcase current research
		Attend primary care patient group meetings
		Advertise studies– posters screens in general practices
Improving the Experience & delivery of research		Patient Research Experience Survey (PRES)
		Patient Research Ambassador Initiative (PRAI)
		Study reviews
		Study walk-throughs
		PPI databases
Training & Education		PPI (for the research community)
		PPI resources (for researchers & public)
		Showcasing the benefits of PPI
		Building Research Partnerships

7.3.1 Activities and initiatives

With the renewed focus on research delivery and engagement, the PPIE objectives were to raise public awareness of specific trials and of health research generally and improve the experience for research participants. The assumption presumably is in the short to long term these will positively impact recruitment rates. One informant summarised the aim of raising public awareness of health research:

> *'So that (when a patient) goes to their GP or goes into hospital they are really, really aware, expect, and are comfortable with the idea that they might be involved and invited to take part in research. It doesn't come as a bolt out of the blue.' 06/S1/SM*

Several initiatives were underway or planned. At Stage 1 some were CRN high level objectives, being piloted in certain locCRNs that became part of the PPI&E Strategy. The initiatives are grouped and presented below.

Improving recruitment to studies – short and long term

Promoting and publicising research primarily by interacting with patients and the public was to be an ongoing activity. Two locCRNs had held events in secondary care to raise awareness and showcase the Trusts' research. These could prove to be a challenge to arrange and ensure good attendance:

> *'It is a tall order to do, because we've run an engagement event … and we advertised it widely … we went on radio and we advertised it and we actually went out into the streets … and gave fliers out … and we got about 10 members of the public turning up … to get members of the public to something there's got to be something in it for them.' 03/S2/SM*

Being more discriminatory about the specific audience was a future aim. Targeted events, for example, condition specific or hard to reach populations had been more successful as demonstrated in this quotation.

> *'We had a lot of stands with studies who had people who wanted to recruit from this population. So they were there and people were able to sign up for the studies or at least get information for the studies. A*

> *really, really good event, we had about 350 people there, so it was very good.' 07/S2/SM*

In another locCRN non-PPI staff regularly attended primary care patient groups as part of a recruitment drive for particular studies. They also signposted other ways of being involved.

> *'They do events and information sessions for the patient groups of those practices, about studies that they might be able to get involved in' […]   and more recently it's also to try and get some.., em, to try and encourage them to think about getting involved in the design, but obviously that's not something that.., we're not involved in the design so it would be just getting them to think about if they would like to be involved in that pointing them in the right direction as to who they could approach.' 08/S1/M*

Improving the experience and deliverability of research

Five initiatives from the PPIE Strategy were discussed. Most had implemented the Patient Research Experience Survey (PRES) and the Patient Research Ambassador Initiative (PRAI). Three other activities mentioned were: study reviews, study walk-throughs and the development of PPI databases.

Patient Research Experience Survey and Patient Research Ambassador Initiative

The PRES is a national initiative. Although it surveys patient research participants it is managed 'under the PPI banner' (09/S2/M). The survey findings 'provides research professionals with a wealth of information which helps to shape how research is designed, conducted and delivered'.[294] Individual locCRNs receive the data to analyse and produce reports for national CRN, for speciality groups and NHS trusts.

> *'What we want to do is go back to those organisations and give them … the national and trust-specific reports and see if we can make any changes to better the experience of patients in studies at those organisations, so we're trying to look at some actions rather than just doing a survey, collecting some opinions and that, so we're trying to get some tangible kind of impact as a result of the survey.' 04/S2/M*

A PRA is described as ‘someone who promotes health research from a patient point of view’.[295] However, the specifics of the role are a matter of negotiation between the PRA and the NHS organisation.[295] The locCRN role is to support NHS organisations with this initiative; some had created a shared web space with resources on the NIHR hub, set up a forum and intended to provide training.

locCRN PPI staff encountered problems with the PRAI and it was resource-intensive in terms of time and effort; some struggled to engage NHS Trusts in the initiative. They said there was a lack of clarity about the PRA role. In some trusts the PRAs are nurses or health care assistants because ‘it’s essentially about being an ambassador for research’ (10/S2/M). This was considered problematic if it was envisaged PRAs could be a conduit to patients for involvement or engagement work.

> *‘It’s just if you specifically want to target patients, for further initiatives, then who your patient research ambassadors are, it’s quite a good place to start but obviously the problem is if you then find half your patient research ambassadors are actually staff that’s slightly different.’*
> *10/S2/M*

Study review

Despite comments about the difficulties of post-funding PPI trouble shooting, three locCRNs reviewed CRN portfolio studies on an ad hoc basis to identify issues that may impact on recruitment. A third locCRN was considering trying this out with their own portfolio studies. Another took the opportunity to review studies that were having problems recruiting with patients who attended PPI training sessions.

Two locCRNs mentioned Study Walk-throughs with patients to identify aspects of a study, struggling to recruit, that may discourage people from participating. One had heard about this from another locCRN at an event and was keen to try; the other expressed the need to test this initiative before adopting.

> *‘We’re beginning to look at now doing Study Walk-throughs for studies that are amber or red, … but I think they need to be tested out because I am concerned that if the study has had PPI at a national level what you don’t want to do again is duplicate that so that it requires multiple protocol amendments.’ 11/S1/SM*

There were database development initiatives at local and national levels. At Stage 2 a few locCRNs were involved in what was described as ‘scoping work’ to identify PPI groups supported by charity and community organisations for a national database. One was unsure of the purpose of this work and the other thought it was to improve access to a range of groups for trouble-shooting purposes in the delivery of studies. Another was developing a PPI group contacts database for each of the 30 locCRN specialties. Finally, with a different focus one locCRN was supporting a local NHS trust to develop a database of patients interested in PPI.

Training/education in research and PPI

Under the banner of training there was a weekly drop-in session for PPI advice, bespoke PPI sessions for research teams and resources and training signposting. Another was events ‘showcasing the benefits of patient and public involvement’ (12/S1/SM). Three locCRNs offered PPI training to their staff and researchers. Another had developed resources for lay people involved in research.

> *‘So we’ve developed a range of things … because I think when you’re doing something like sitting on a panel for an NIHR study you really need to have some experience, and to have some confidence … when you’ve got a collection of professors and doctors … statisticians, you could really easily be blown away by that and not be able to speak and then you’re not being involved. ‘13/S1/M*

Some ran broad educational workshops with patients and clinical/academic researchers about research or more practical ‘how to’ sessions on PPI for the study duration. These went beyond PPI delivery and encompassed research priority setting and design.

The Building Research Partnerships (BRP) was the locCRNs main training resource. This is a revised version of the National Cancer Research Network's (NCRN) Patient and Public Involvement Induction Training[296] (p6) the NCRN had been running since 2007. It is designed to inform and advise on practical ways patients and the public can be involved in research.[297] BRP consists of a set of materials and resources designed for workshops or short sessions, for researchers, patients and the public. The materials, available via the NIHR website, include 13 resources spanning an introduction to research and methods, to ways patients/public can be involved, through to recruitment, guidance for facilitators and an evaluation plan. It was acknowledged that before BRP investigators were expected to involve patients/public in research but there was little guidance or support available.

> *'It's all very well saying like "We want people in to do this, that and the other", and then saying "Well how do those people know how to do it?" and right up until this last year we didn't have an answer for that, it's only because of ... Building Research Partnerships now that we … know how to do it. … we've got a resource now that we can support them.' 13/S1/M*

There were some issues with the BRP workshop/sessions. It overlapped with the training and support locCRNs offered to NHS trusts and PRA. Only a small component of BRP covered research delivery, though one locCRN had tailored the materials to their needs. Not all locCRNs' PPI staff had the requisite skills to deliver the BRP. Achieving the suggested mix of patients/public and researchers in sufficient numbers could be difficult. Some locCRNs were reliant on NHS trusts to identify potential attendees. Finally, one informant believed patient/public BRP attendees should be able to learn about further participation or involvement opportunities at the sessions, but it was often difficult to have everything aligned.

7.4 Latent analysis to identify barriers and enablers to sharing and collaboration

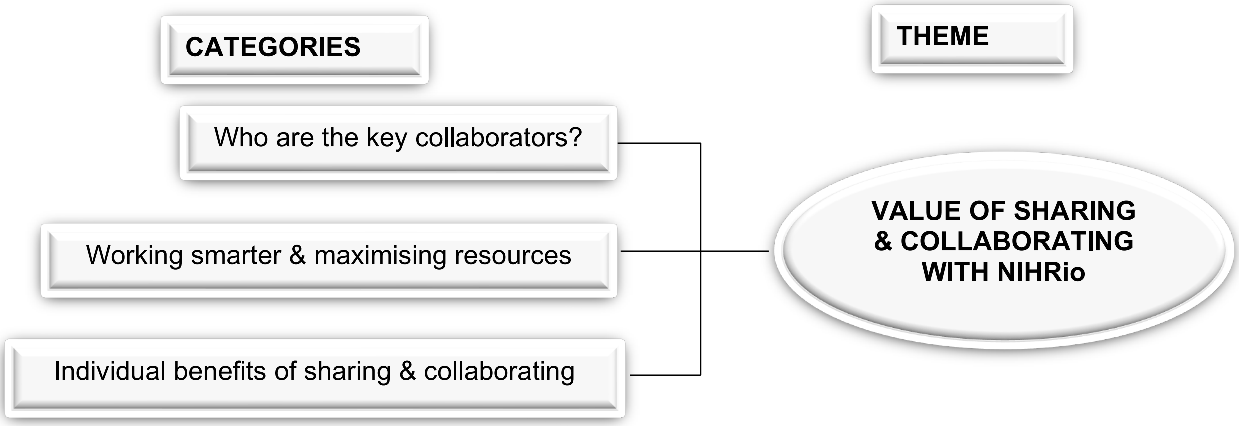
Experiences and views of sharing and collaborating with others in a PPI role were explored. The potential avenues for the locCRN to share PPI resources and collaborate were with NIHRio and/or NHS, academic and other partners regionally and with other locCRNs and NIHRio nationally. The three overarching themes identified from the abstraction of categories are presented below: ‘Value of sharing and collaboration with NIHRio’, ‘PPI Boundaries’ and ‘Communicating to facilitate sharing and collaboration’.

7.4.1 Value of sharing and collaborating with NIHR infrastructure organisations

From informants’ accounts locCRN PPI had two main purposes. The first was to deliver upon the PPIE Strategy objectives agreed with the CRNCC. Several of the objectives were used by CRNCC as performance metrics. The second purpose was to support researchers of CRN portfolio studies with PPI. These two strands of activity are key to this theme as they raise questions about the value of sharing and collaboration with NIHRio.

This theme was abstracted from three categories: ‘Who are the key collaborators?’, ‘Working smarter and maximising resources’ and ‘Individual benefits of sharing and collaborating’ (Figure 7.4-1).

Figure 7.4-1 – Categories within the ‘Value of sharing & collaborating with NIHRio’ theme



Who are the key collaborators?

Achieving the PPIE Strategy objectives was a key motivation for interacting with others regionally in a PPI role. This was expressed more keenly by the informants who had a senior role within the locCRN. Two examples of these objectives were the Patient Research Ambassadors Initiative (PRAI) and the Patient Research Experience Survey (PRES). Post-transition, there was a greater need for locCRN PPI staff to forge or renew links with NHS trusts and Clinical Commissioning Groups (CCG) as they were the primary route to deliver these specific objectives. For example, the PRAI was NHS trust-led but heavily supported by locCRN who were expected to register the number of PRAs (which was also a CRNCC metric) and provide training and support the individuals in that role.

As most locCRNs no longer had their own patient groups (PG) they needed to access these through other routes. The NHS trust PG were identified as a key resource. One informant identified opportunities through their NHS trusts to access PG and deliver other initiatives. Another locCRN was planning to meet with local NHS trusts and look for opportunities where they could ‘piggyback’ and roll out specific CRN initiatives.

> *‘There are initiatives to roll out various strategies around (area) so by linking in with people who have already got or have set up some PPI initiatives in their own trust so in (area) there’s (name) NHS Trust and they had a PPI forum so one of our action points is to speak to them and see what they’ve done rather than re-inventing the wheel and it’s a way of trying to roll (survey) out so I think what we’re going to try and do is link in with as many people who’ve already done it um and then try and piggy back on them to um say ‘Okay you’ve got your forum can we roll out this NIHR initiative?’. 01/S1/M*

Trying a different approach, one locCRN had set up a working group with NIHRio and NHS partners. The focus of the group meetings was strategic, with an emphasis on exploring how to implement initiatives from the PPIE Strategy as opposed to pragmatic matters such as sharing resources.

> *'For me it's been a little bit about 'Okay, what is our local strategy?' so I'm defining what I think in (region) we need to be establishing as a local strategy in line with the certain things that are coming down nationally that they want to see us all participating in, so trying to join up the two and create a baseline.' 02/S1/SM*

Where locCRNs had no previous links with NHS trusts, the first task was fact-finding about PPI and exploring opportunities to share resources and offer support. As only one locCRN had worked closely with NHS partners pre-transition, a large part of the work for the remainder was establishing links with these partner organisations as some regions had as many as 16 NHS trusts and 19 CCGs. Some informants were unsure who in the NHS trusts to contact about PPI. One informant argued it was difficult to move forward on the objectives without a level of baseline PPI intelligence.

> *'What I'm trying to establish is a two-way conversation. I can help you with some stuff … and in return it's the little bit of feedback, the case studies that are needed, 'What are you doing? What's happening? How many PPI reps (PRAs) …?' All the information that you need to feedback nationally, getting them involved in the training courses that are coming down nationally.' 02/S1/SM*

At the Stage 2 interviews understanding the regional PPI landscape and keeping abreast of the changes and developments remained problematic. This could be due to the sheer number of organisations and or the region's size.

> *'It is hard to link in with the patient and public involvement and to know exactly what's going on across the geography of the whole of (area). … I try to keep a handle on everything that's going on but obviously I can't know everything because as well as the different organisations, there's 32 different (clinical) specialities … so it's hard to kind of keep a grip on everything that's going on.' 03/S2/M*

The other locCRN PPI role to support researchers was discussed less by informants than that of delivering upon the PPIE Strategy objectives. When it was mentioned, the same route for support was from the NHS trust PG. However, the issue of a lack of awareness of where these groups were and how to access them was raised again. Informants who were aware commented that a 'very rich' infrastructure of patient groups already exists.

> *‘If (a study) is struggling (to recruit) just locally …normally we would take it to one of the existing groups that are available to us because there is such a wide group of trained patients that we can use for accessing … for that kind of work. […] So there’s really very little point in us duplicating that service in any way whatsoever. So a lot of the work in that area is for us to signposting both researchers and our delivery teams to where good advice may be.’ 04/S1/SM*

The process of linking with other NIHRio about PPI was raised less than efforts to connect with local NHS trusts and only two informants talked about it. One thought it an important step towards working out ‘how we can join together’ (05/S2/SM) and another to build a regional picture of PPI. Another said:

> *‘I’ve been linking with all the other agencies if you like, that offer a PPI input, so that’s the local CLAHRC, and the (university) partners who also have a group of PPI people. So I link in with those, so this year was about, making sure that we all know who each other are and what’s going on.’ 06/S1/SM*

Working smarter and maximising resources

It was acknowledged that PPI is ubiquitous in NIHRio and ‘everyone is working in silos or doing a bit of PPI’ (07/S2/SM). For this reason, several informants said there was the potential for duplication of activities. Duplication in this instance could mean replicating an activity regionally or ‘reinventing the wheel’ by developing something already in existence.

> *‘There are all of these different organisations under the umbrella of NIHR and in the future surely that’s all got to come together otherwise it’s a duplication and a waste isn’t it? That’s what I think. I can understand where we are where we are because we all started off in different little networks and grew.’ 06/S2/SM*

Duplication was considered a waste of resources. Some informants alluded to the fact their budget for PPIE was smaller post-transition and they had to be creative in their use of resources. Sharing and collaborating on PPI regionally was an opportunity to maximise resources or as one informant put it, to ‘work smarter’

(08/S2/M). With the loss of PPI staff and an increased workload, collaborative working was a future necessity.

There were also reports, particularly at Stage 2, of difficulties recruiting to vacant posts. One locCRN was joining forces with academic and NHS partners to fund a shared PPI post as they had identified duplication of roles. With a strategic aim, and one that may also maximise resources, another locCRN had gone beyond the model of establishing a cross-regional PPI Group to facilitate collaboration. They had decided along with local NIHIRio to jointly finance a single post to guide PPI regionally.

> *'So what we're having now is … all the different bits of NIHR infrastructure in (region) … are all going to contribute into a pot and employ a strategic lead for PPI so that there's an overall PPI strategy for the whole of (region) and then that strategy will then be flowed down to the PPI offices in the various bits of the infrastructure.' 07/S2/SM*

There were a few examples of sharing across NIHRio on specific PPI activities. One was an agreement with another NIHRio to have news items or information published in their newsletter; this meant the locCRN did not have to establish their own database of contacts. One other initiative being piloted at the time of the interviews, developed in conjunction with NIHRio in the region, was a PPI Training Share Bank.[298] This scheme aimed to maximise resources by sharing expertise and 'exchanging services and training'. The locCRN was providing some funding for travel and expenses for involved patients.

> *'Where you provide a service to somebody and then that person reciprocates with a service that you need …So it's very much like an exchange of services and training between organisations […] they've got lots of courses trained up, but the RDS is part of it as well. So they'll all jump in and there's all sorts of different support and training for patients and public and researchers in there.' 02/S1/SM*

To avoid duplicating PPI activities themselves some locCRN informants were scoping what was happening regionally. With no plans to run a BRP workshop, one informant was exploring the PPI training other NIHRio and universities in the region had to offer; thinking it pointless to develop training when others in the region had the expertise:

> *“But from a training point of view I’m now having a look to see what the rest of the NIHR platforms and the university are doing because if they’re doing training courses I’m not going to put ones on because they’ll be doing them way better than we could, just by cobbling something together.’ 05/S2/SM*

Another potential solution to duplication was for locCRNs to raise awareness of their PPI resources across NIHR. Again ‘training’ was identified as something with the potential for duplication and for sharing.

> *‘The idea is that we … roll it out as a universal PPI in research training across all the 15 CLRNs but … we should work collaboratively with our NIHR partners. making sure they understand what training we deliver so if there is any development that they are doing it isn’t duplicated.’ 08/S1/M*

The activity most delivered together across locCRNs was the BRP Programme. One informant partnered with a neighbouring locCRN, due to concerns they would not be able to generate a large enough group of attendees to justify running it (05/S2/SM). Another reported they were taking the opportunity to draw upon the resources of another locCRN in the delivery of the BRP.

> *‘In our neighbouring network I’m just in touch with somebody who is running them and has too many facilitators and too many Building Research Partnerships on so actually I’m thinking we could just team up or we’ll send people up there because there’s an opportunity there.’ 09/S2/M*

Another worked with a neighbouring locCRN to hold an event to facilitate learning and sharing but also to support each other in delivering their objectives and implementing PPIE Strategy initiatives.

Individual benefits of sharing and collaborating

Most of the interactions, or intentions for interactions, described above were locCRNs drawing upon the resources of others rather than collaborating or sharing. This calls into question what NIHRio PPI have to offer each other and the value of sharing and collaborating.

Three of the locCRNs had created a regional group of NIHRio PPI staff or adapted one already functioning to facilitate collaboration between the locCRNs and NIHRio locally. The impetus for the first new group was INVOLVE ‘where we need to meet and look and see where we’re meeting the six recommendations and things for Going the Extra Mile’ (10/S2/SM). The second stated they formed the group because ‘the message from the co-ordinating centre is we should be working together.’ (09/S1/M).

There were some positive comments about the group model. One informant said it had helped to establish ‘really good relationships with the RDS, with the CLAHRC, with the BRC around PPI initiatives’ (10/S2/SM). Another reported this group had resulted in different workstreams for the members to work on together (09/S2/M). The third gave an example of a collaborative project they had begun work on.

> *‘If we’re delivering some training how can we deliver something and the RDS do something as well but not duplicating each of the areas, but complementing each other’s work.’ 08/S1/M*

However, it was acknowledged this was not a quick fix: ‘(group) was launched a couple of years ago and it’s taken some time to get some momentum‘ (08/S1/M) Another informant, who had *joined* an established NIHRio PPI group, reiterated that progression to collaborative working was slow:

> *‘That meeting at the minute is about sharing what we’re doing rather than planning.’ 05/S2/SM.*

Outside of the group model only one informant suggested a resource they could share of value to other NIHRio. As mentioned earlier locCRN accessed patient groups for their input to support researchers whose study was struggling to recruit. This was raised as a potential useful resource for researchers when they are developing research proposals. This informant said they had been encouraging their NHS partner organisations to build a PPI database to enable researchers to seek the involvement of research naïve patients rather than those experienced in PPI.

> *'We don't necessarily design studies, we can identify members of the public who can support that design because we work in the NHS. […] if the chief investigators if they use the RDS … if the RDS have got PPI already but what we find is sometimes is the types of patients are involved are almost expert patients, they're not always real patients.'*
> *12/S2/SM*

This issue of the types of patients/public NIHRio involve in research design and/or delivery was raised by another informant and questions the value, in certain circumstances, of sharing PPI groups as a resource across NIHRio. They talked about their own preference to involve patients identified through contacts in the NHS Trusts who are not part of a PPI group.

> *'I think people have really different viewpoints and models on what PPI should look like and that's been really apparent when we've done the cross-regional work because (two NIHRio) they're very wedded to groups they work with who are experienced, who have been trained, and individuals as well who are experienced PPI people basically.'*
> *09/S1/M*

Few mentioned the potential gains for others of sharing and collaboration. Although reducing duplication may help stretch NIHRio's PPI budgets, it was difficult to envisage the benefits for those in an NHS trust PPI role. From some informants' accounts, NHS staff perceived collaboration as NHS staff taking on the work of the network.

> *They'll very vocally say "I've got a day job. I work in (NAME) Trust … I have to do things for (TRUST), I can't pick up work for the network".*
> *02/S2/SM*

Another informant alluded to the fact that those responsible for PPI in NIHRio, NHS trusts and academic institutions may be wary of collaborating with locCRN – possibly, as highlighted above, because they perceive it as incurring extra work. Also, in their description of their initial approach to other PPI staff these informants convey the perception of a difficult landscape not conducive to collaboration.

> *'So I'm just getting those meetings booked in to say "Hello, I'd like to work with you, I don't want to be in competition with you, if you've got stuff I can nick I would absolutely love that and what can we do to support you?" There's always that view of the network that they are going to swoop in and take it all off them.' 05/S2/SM*
>
> *'I don't want to do what you are doing, I don't want to take away from what you are doing I just want a little bit of communication, and that's what we're trying to sort out at the moment.' 02/S1/SM*

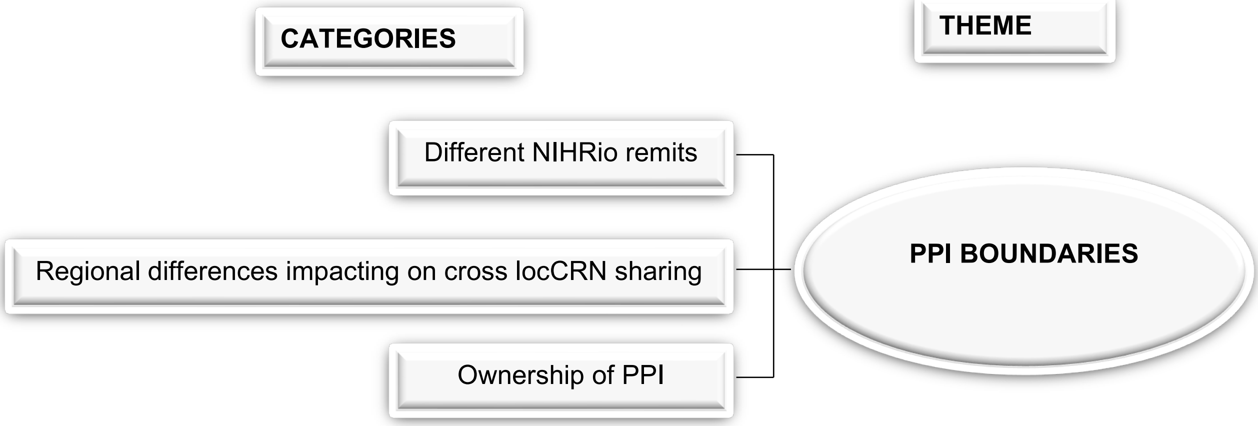
7.4.2 PPI Boundaries

Some informants did not appear to view all NIHRio as one organisation. The term 'boundaries' between locCRN and other NIHRio was often mentioned.

> *'We can actually go across those boundaries and deliver training to their groups and their services.' 01/S1/M*

Boundaries of NIHRio remit, locCRN regional differences, and PPI ownership that impacted on PPI sharing and collaboration were identified (Figure 7.4-2). These will be discussed in turn in the subsequent sections.

Figure 7.4-2 - Categories within the 'PPI Boundaries' theme



Different NIHRio remits

The remit raised by informants in relation to barriers/enablers to sharing and collaboration was where in the research pathway the NIHRio sits. For example, RDS focuses on the development of ideas into research proposals and the locCRN on the delivery of studies to time and target.

One informant did not consider remit as either an enabler or a barrier but thought it important to be aware of the differences. Acknowledging these differences meant they could ensure their own PPI complemented what was offered by other NIHRio.

> *'We're trying not to duplicate what's already in the system so signpost accordingly but also support researchers where there's a need. Because we are very, very conscious that everyone has a role; the RDS at the study set up stage, we have the AHSN, we have the innovation bit, we've got ourselves in the delivery arm. So it's trying to make sure that we offer an additional bit of service really so that we're not duplicating what's already there.' 02/S1/SM*

A few informants thought of the different remits as enablers for collaboration. One locCRN said they provided a rationale for collaboration on certain initiatives. For example, they worked with two NIHRio regionally to run the BRP Programme. This was felt to be more appropriate as the programme encompasses the whole research pathway rather than just research delivery.

Another informant alluded to the fact there is a certain amount of protectionism happening with others in a PPI role regionally. Due to this, the different remits are liberating and advantageous as the risks of encroaching on the work of others are reduced or removed.

> *'We are expected to work as partners in a collaborative way but not putting the network above or beneath any of the others. Also it means that potential tensions that arise because people feel you're treading on their toes or moving into their territory … don't arise either because*

> *actually there is nobody else sitting in the delivery space from a PPI point of view.' 03/S2/SM*

In contrast, others thought the different remits led to silo working. Another said collaboration with NIHRio across the region was easier for some activities than for PPI regardless of their individual remits.

> *'I think we're all told to share and play nicely together but I think that there are.., everyone's doing their own thing to some extent ... and that is because the remit is slightly different.' 04/S1/SM*

> *'AHSN, CLAHRC, RDS … we're all funded by the NIHR … but … you have to recognise that each strand has their own role remit and yes we would try and work across it … especially when research studies come out ... in PPI not as much if I'm honest.' 05/S2/SM*

Clarity regarding specific PPI remit was said to be important. One informant said after the transition this had not been made clear in other regions and created 'quite a lot of tension' (03/S2/SM). A lack understanding of their remit was a hindrance to joint working. This comment also suggests collaborative groups need a shared vision and goals to ensure everyone can engage.

> *'I think it's really difficult to say to people – which is what the Co-ordinating Centre is doing now – "You need to work in collaboration with your other partners" as in fact people don't have the confidence in what their business is. If you've got three or four parties who are all trying to work on supporting grant development and people do feel "Actually how do I fit in to this? Where does my job sit in this?" it's not then a good place to do the constructive positive work.' 03/S2/SM*

NIHR was said to be a complex organisation and even those working within it struggle to understand where and how everything fits together. A lack of understanding of the remit of others responsible for PPI, and of how their *own* work fits with other NIHRio was mentioned. Even when informants reported they had a good understanding of the remit of other NIHRio, this was sometimes not the case. One informant did not fully appreciate the scope of the work of RDS in terms of PPI.

> *‘The Research Design Service, they seem to want an application to look at, it would be better if they had a bigger kind of consultation process where researchers came to them and said “Oh my ideas are this, and I’d love to talk to some people about it”, before they firm it up and put it in a funding application you see, and I think that’s where we’re missing a trick.’ 04/S1/SM*

Regional differences impacting on cross-locCRN sharing

For national working, the main forum for sharing was the national CRN PPI leads meeting. Although it was acknowledged this meeting provided learning opportunities the differences in the size and structure of the regions meant the experiences and initiatives of certain locCRNs were not always of use to the others. Regardless of the success of an initiative these are not always replicable across locCRNs due to the regional differences.

> *There was a presentation (other locCRN) who have done lots of things together and worked really closely with CLAHRC and RDS and the other.. organisations. but they haven’t got many hospitals … so you could try and do what they did (here) with three, four massive teaching hospitals, … but it just doesn’t work. So I get that thing about, actually that’s a great initiative for you but it’s not necessarily going to work for us.’ 06/S2/M*

Ownership of PPI

There were definite boundaries of PPI ownership identified within NIHRio and NHS trusts that hindered sharing and collaboration. Some of this was attributed to a heavy workload, part-time PPI posts, logistics and silo working. However, one informant thought the transition was in part to blame for the difficulties experienced in engaging NHS trust staff. They talked about a hiatus in PPI during the transition where, in their experience, the locCRN lost control of PPI.

> *‘I think the interesting point is that the first year of transition of the network there was no real national directive for PPI … and trusts just picked up the baton and carried on and didn’t engage because they didn’t need to engage, it was no longer the network’s interest or responsibility and […] then in the second year now – because obviously we’re waiting for the strategy to come out as a finalised document – there’s now ‘Oh we need to be doing this’ […] but never*

> *really established … regained control of this as a network and leading on PPI.' 05/S1/SM*

Other informants commented on NHS trusts taking on the ownership of PPI and being reluctant to work with external partners. NHS Trusts had formed patient groups they were 'very protective of' (07/S2/SM).

> *'And then you've got the trusts and they seem to be doing their own thing as well don't they? They seem to have their own patient groups and they don't want any interference and things like that. It is very complex.' 04/S2/SM*

Two informants had offered small financial incentives to NHS trust PPI staff to engage, the first to help them achieve one of the national objectives and the second for more altruistic reasons. In the experience of the second informant, this had not been fruitful.

> *'My only incentive … is that they can come with an idea … that will make a difference locally, may hit one of my national, tick-boxes that I need to do, and they can get some money to actually do that.' 05/S2/SM*

> *'There are research nurses who have groups and we try to support them and we try to find out who they are, who the groups are, what their events are and then we can publicise them, so generally all they want is us to pay for the teas and coffees (laughs) and we don't get any feedback. Our budget is a lot smaller so we've got to start focusing how we use that money a bit better.' 07/S2/SM*

Similarly, engaging regional NIHRio PPI staff in sharing and collaborations was not always easy. Difficulties generating interest in sharing and collaborating were not isolated to one or two locCRNs and one informant reported their experience was not unique. They believed people are reluctant to share what they believe they have worked hard to develop or build.

> *'I find it difficult to get engagement and I know other (locCRN), I've had similar conversations with them. … it's difficult because people are doing a job with a particular remit and a particular focus and then*

> *suddenly they are being asked to overlap with everybody else … it's not kind of what they've been doing and it's always difficult to get people to change isn't it.... we should all be partners working together, but in reality that doesn't always happen, like any structure, to be honest. It's not unique, it's just human nature'. 08/S2/M*

In contrast another informant believed there was an ethos of sharing across NIHRio but there were geographical and work-related barriers. They thought it unlikely any NIHRio would refuse to help another, but in their experience this rarely happens as the relationships are not established. There was consensus that lack of time and logistics contributed to this lack of engagement, though informant views differed as to whether silo working was partly responsible. Notwithstanding the view that people are too busy to engage with others on PPI, another opinion was some people never think about collaboration. Those in a NIHR PPI role do not exclude other NIHRio but neither do they fully involve them; for example, NIHRio may be invited to *attend* an event but not to be involved in its *planning*.

> *'It's trying to get people to stop, pause, involve everybody else rather than just running off and doing it. And it's … that's not the culture and it's not the way it has been, it's been a 'do something, perhaps tell people that you've set it up and they can come along rather than how can we do this … it's just a change in the … it's sneaking in there that we need to be joined up and working as a whole.' 07/S2/SM*

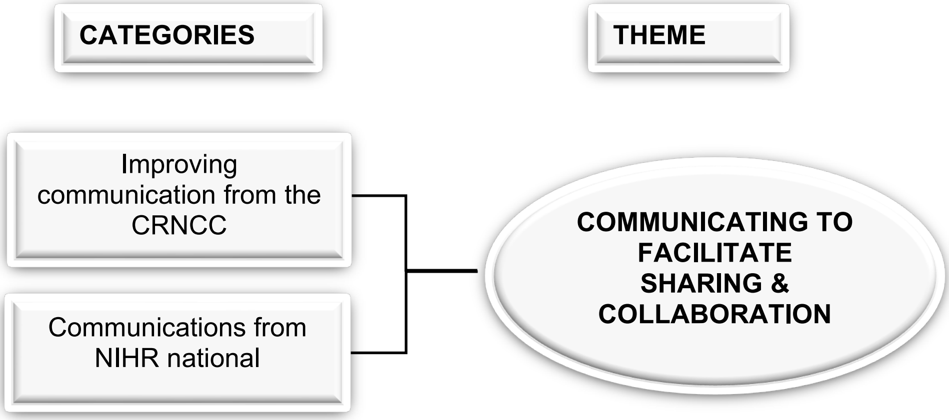
Informants were asked about cross-locCRN sharing. Though most informants believed there was an ethos of sharing, a few reported that some do not always share or contribute and when they do it tends to be the same people.

> *JL: And are people actually sharing?*
>
> *INT: Yeah mostly. It varies obviously. Different people are more precious about their things and feel like they own things and stuff but mostly people are pretty good.' 06/S2/M*

7.4.3 Communicating to facilitate sharing and collaboration

This theme encompasses communications from NIHR that may impact on sharing and collaboration at a regional and national level. How the One NIHR campaign was interpreted by informants is included. Two categories were identified: ‘Improving communication from the CRNCC’ and ‘Communications from NIHR national’ (Figure 7.4-3).

Figure 7.4-3 - Categories within the ‘Communicating to facilitate sharing & collaboration’ theme



<u>Improving communications from the CRN Co-ordinating Centre</u>

There was praise for the CRNCC and their role in facilitating sharing across the locCRNs. They were said to be ‘very good at wanting to share everything’ (01/S2/SM). Another informant mentioned a ‘really comprehensive’ monthly PPI update from CRNCC ‘with things that are going on nationally with PPI’ (02/S2/M).

> *‘I think they’ve got better at that nationally, so they’ve got a really good national team together now and I think over the last year that has improved massively. So they’re meeting us regularly, they communicate with us regularly, we’ve got a much better sense of who’s who and who’s looking after what and what we are supposed to be doing for our plans, and lots more support really.’ 03/S2/M*

Only one informant was unhappy with both the CRN PPI national meetings and communications from CRNCC. They felt the meetings were a missed opportunity and should generate actions to encourage more cross-locCRN working and sharing of ideas. The meetings involved the PPI leads only and information from these may not always be cascaded to others in the PPI team.

> *'It's a difficult one because all networks operate differently and so I don't know what's going on in different parts of the country from a CRN point of view […] The head of PPI's all meet every month, so they have their teleconferences, they have their meetings, and they have their national updates and stuff like that, but I think it needs to go a bit beyond that.' 04/S2/M*

Their second critique was disappointment that information on the PPI activities of other locCRN was not forthcoming. They believed potentially invaluable locCRN opportunities to share experiences are missed and this is a failing of the CRNCC communications.

> *'It would be good to see what's going on in different parts, and the Co-ordinating Centre's role should be exactly that, to share what's going on in the (other regions), […] there's a lot of time that could be saved if someone's already done something, can I just ring someone up, and say "Listen, this is what I want to do, can you send me your resources, or your plan", and it's done. 04/S2/M*

There were other comments about unhelpful communications from the CRNCC regarding sharing and collaboration. Although they admitted they had a long history of collaborative working on PPI across their region, one locCRN expressed frustration over the volte-face of the CRNCC.

> *'The feedback nationally now, which was "You" - say RDS, CLAHRC and whatever – "will not work together" to "You must be working together and you must evidence in your plan". We have gone full circle with that.' 03/S2/M*

Apart from this about-turn on collaboration from the CRNCC, there were some other criticisms of their communications with NIHRio. This led to scepticism around the broader messages about greater collaboration. Experience had coloured a few informants' attitude to collaboration when *shared* events had been left to the locCRN to lead:

> *'It's the different messages that are passed down to each of those organisations … probably by the back door "Well you don't need to lead this, leave it for so-and-so to lead" and that doesn't become One NIHR, because One NIHR would need everybody to be an equal. … So*

> *yes, we all go “We’re One NIHR” but in reality I don’t think it really works that way.’ 05/S2/SM*

<u>Communications from NIHR National</u>

As illustrated in the above quotation, One NIHR was perceived as treating all NIHR staff as equal. All informants were aware of One NIHR though only two people referred to it without prompting: for one it was a strategic theme; the other had instigated a One NIHR Meeting that included several NIHRio. When asked about the meaning of One NIHR, a few Informants mentioned the ‘I am NIHR’ badges available to NIHR staff and the ‘One NIHR’ website; they regarded it as Communication team ‘message’ or another NIHR campaign. One person stated it had begun as a message but had evolved:

> *‘I think it started out like a strapline, but it’s developed, we don’t call it One NIHR family anymore. … we should do it anyway, we are all One NIHR … I feel like we are One NIHR. It started out as an initiative and … and I do feel like we are.’ 06/S2/M*

> *‘It was mentioned when it was initially introduced but to be honest no mentions One NIHR at all. …. I have a badge somewhere with ‘One NIHR’ on it. And I think one of the things is nationally you had the ‘Okay to ask’ campaign, now it’s ‘I am Research’ so it was like has ‘Okay to Ask’ been phased out? … so it’s a type of change and I think a lot of people then get fed up with all these changes. Like “Which campaign is it now?”’. 04/S2/M*

The majority view was that One NIHR signified the establishment of a joined-up way of working across the NIHRio. When explored in greater depth, the perceived rationale for working together was striving for a reduction in duplication in activities and increased sharing of resources.

> *‘My understanding is that (One NIHR) means that it’s not just the networks who respond to PPI, we are meant to share resources but not duplicate things that are going on elsewhere … But I think One NIHR is meant to be that you’re all working together for the same thing but you may come at it from different angles or at different points in the life cycle.’ 02/S2/SM*

Although not a common view, one informant commented that One NIHR also meant standardisation across locCRNs to ensure those engaging with the network had the same experience or received the same (or similar) service wherever they went ‘which is what didn’t happen in the previous networks.’ (07/S2/SM).

There was a varied response to the concept of One NIHR, regardless of its interpretation. A few people remembered when it was first launched but said there was very little resultant activity, particularly in relation to PPI. One informant, although they were aware of One NIHR, said they were not ‘pro-actively doing anything’. (05/S2/SM) . Another commented that the whole thing had ‘died down a bit now’ (08/S2/SM).

Even if One NIHR was acknowledged as a ‘move to make us work more closely together’ one informant was critical of the way the message was conveyed without any plan for implementation or evaluation.

> *‘One NIHR is fine but it has to be backed by the annual plans of CRN, RDS, CRFs – all of them – to say what collaborative PPIE demonstrates that we are One NIHR. That would string it all together. …It’s very difficult to change people’s annual plans and that’s why you need long term thinking. You can’t just come up with ‘Oh let’s call ourselves this or that’ and expect it all to join up. 01/S2/SM*

7.5 Summary

PPI Provision in the locCRN

Some locCRNs had struggled to determine what level of PPI was feasible at the delivery stage. Data were collected at a time when the locCRNs were undergoing a period of upheaval and new initiatives were being introduced. However, there was scope within these initiatives for sharing and collaborating with other NIHRio. These ranged from the Patient Research Experience Survey data, which would be invaluable in designing studies, to creating opportunities for involved patients and public.

Sharing and collaborating

Without doubt the transition had an acute impact on some locCRN PPI. In retrospect there were several missed opportunities specifically with the CRN supported patient groups. The CRN transition would have been the perfect opportunity to direct these patient groups with expertise in specific stages of the research process to the relevant NIHRio. The PPIE Strategy was launched late at the end of the transition year. Being aware of initiatives such as the PRAI when the patient groups were disbanded, or moved to other organisations, would have been the ideal time to offer this and other opportunities for being involved in NIHRio.

locCRN PPI staff identified the need to collaborate across NIHRio to maximise resources, but to deliver on the PPIE Strategy objectives they were required to interact with NHS trusts. It was difficult at times to envisage what the individual benefits would be for other NIHRio or NHS trusts to share and collaborate with locCRN. It is surprising that only one locCRN received a directive from the CRNCC to say they should collaborate across the region. The likelihood is that for other locCRNs, delivering the objectives on which they would be directly measured took priority and these became the focus for any local collaboration.

Boundaries of PPI remit were viewed positively by some and negatively by others. Sharing examples of how regions have overcome these differences would be beneficial. Ownership of PPI was an issue, and a few informants perceived a lacked trust in others. Sharing across locCRNs could be improved through better communication but regional differences meant initiatives that were successful in one locCRN may not work in another.

Most were happy with the various modes of communication from the CRNCC. There was one dissenting voice who made some very valid comments about the group meeting and the on-line communications. It is unfortunate that there is no forum for PPI staff who are not leads to express their views. Again, the One NIHR campaign was interpreted as a move to more co-ordinated way of working which raises questions about how NIHR communicates.

In summary, the locCRN data painted a complex picture with major changes in the structure of the network, in the focus of PPI and a loss of PPI staff. They were also under pressure to meet certain objectives set by the CRNCC and this, rather than best practice, was key in deciding with whom they should collaborate.

Chapter 8: The bigger picture - cross-case analyses and triangulation of knowledge-sharing and collaboration, and synthesis of resources data

8.1 Introduction

The rationale for the comparative case study was to determine if a seamless model of NIHR PPI from design to delivery is feasible and if so, what would that model look like. The objectives were to address two key questions:

- What is NIHR PPI provision from research design to delivery: what is shared and what is duplicated across NIHR?
- What are the barriers and enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?

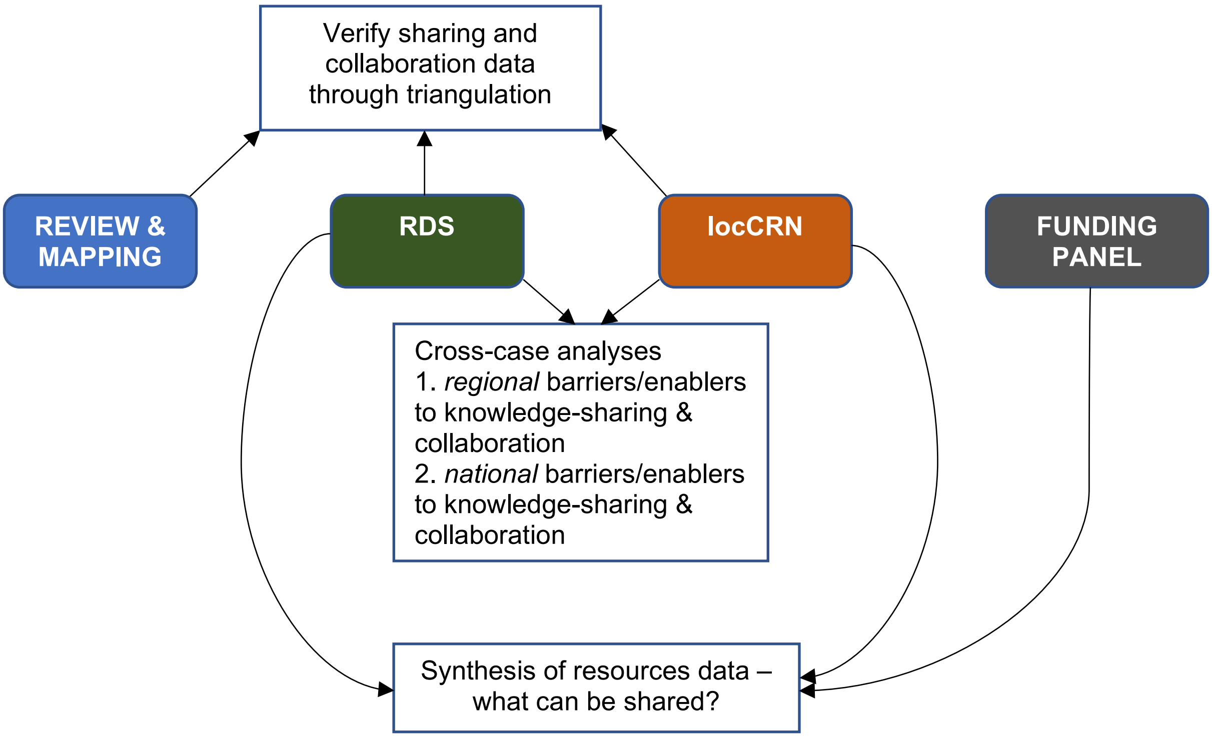
Earlier chapters provided a snapshot of NIHRio regional sharing and collaboration, described PPI provision and highlighted the barriers/enablers to regional and national knowledge-sharing and collaboration *within* the RDS and locCRN cases. In this chapter, the data are brought together for three purposes. First to synthesise the resources (that pertain to training as well as people) identified from the manifest analysis of the RDS and locCRN data with the funding panel interview data to answer the question ‘What could be shared across NIHRio?’. Second, to verify data on sharing and collaboration from the RDS and locCRN interviews and document review of NIHRio PPI through a process of triangulation. Third to build a picture of the dominant overarching barriers/enablers to knowledge-sharing and collaboration, regionally and nationally, through cross-case analyses of the RDS and locCRN interview data and propose solutions to the barriers. This consists of two analyses, one of regional and one of national barriers/enablers to knowledge-sharing and collaboration. The synthesis of resources will address the question of whether a streamlined model of PPI is possible and suggest what this model would look like.

The chapter will begin with a brief description of the data synthesis, triangulation and cross-case analysis methods. In Section 8.3 the opportunities for sharing from the data synthesis of resources are presented. This is followed by the findings from the triangulation. The cross-case analyses are presented as: the antecedent barriers and enablers to regional knowledge-sharing and collaboration, to the act of regional collaboration; then to national knowledge-sharing and collaboration. Proposed solutions are also given for each. The chapter concludes with reflections from direct experience with a regional PPI group and a summary of the key messages.

8.2 Methods

The processes and the sources of data are briefly described in the following sections with an overview in Figure 8.2-1.

Figure 8.2-1 - Overview of data sources, triangulation, synthesis and cross-case analyses



8.2.1 Synthesis of RDS and CRN resources and funding panel data

In the interviews, details of RDS (Chapter 5) and locCRN (Chapter 7) resources, and training, resource needs and skills and experience of public members of funding panels were collected (Chapter 6). These data were incorporated into a matrix to identify duplication and opportunities for sharing.

8.2.2 Triangulation

Data (from different sources) and methodological triangulation (data collected through different methods) of the RDS and locCRN interview and NIHRio document review data was conducted. The triangulation process involved entering the regional sharing and collaboration categories from the QCA of the interview data and the codes representing collaborations, resources and activities for each region from the document review into a matrix (Table 8.4-1). Next, data from each source was compared to search for discrepancies and agreement in the RDS, locCRN and wider NIHRio reports of sharing and collaboration regionally.

8.2.3 Cross-case analysis

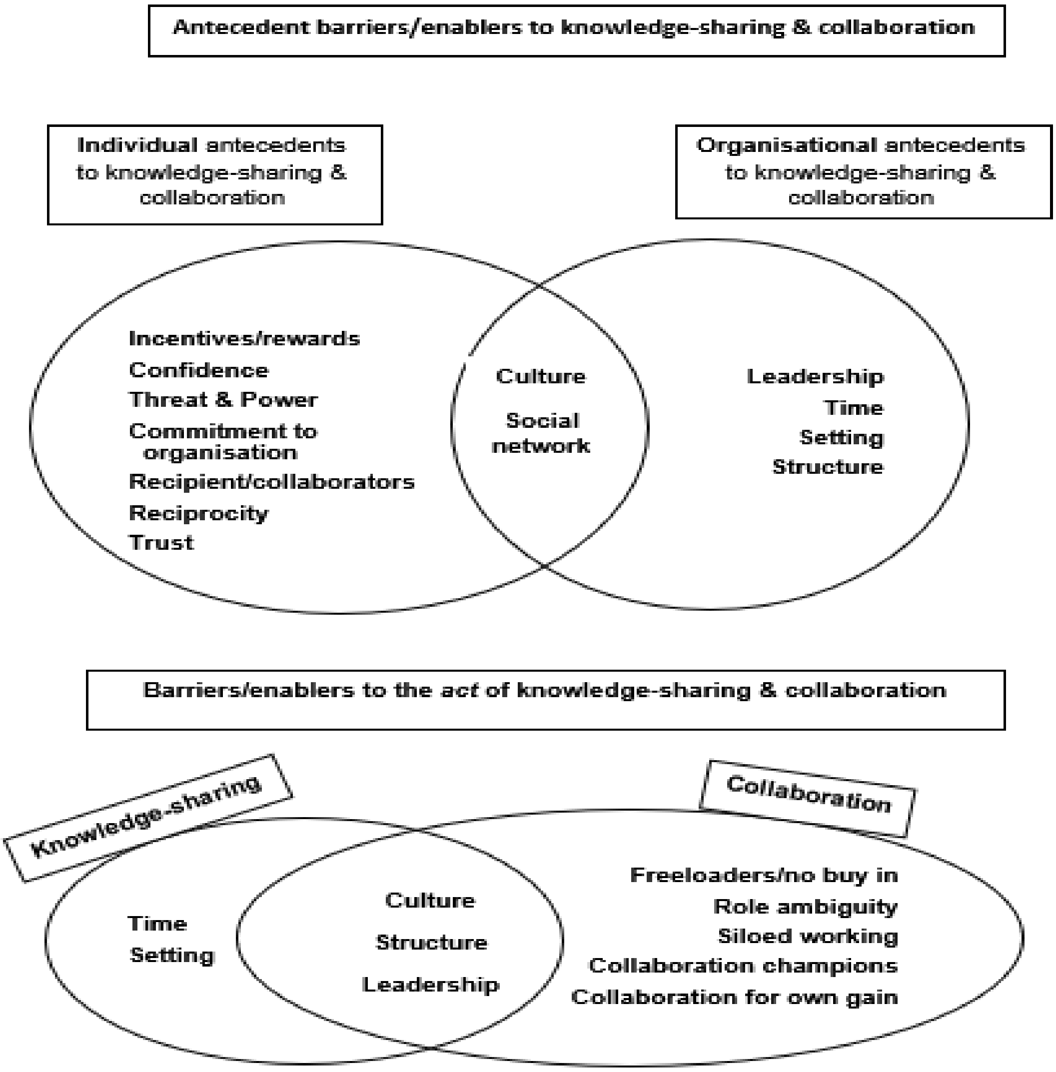
Chapter 3 includes a detailed description of the methods undertaken for the cross-case analyses. A reminder of the key five steps is provided in Table 8.2-1.

Table 8.2-1 - Steps in cross-case analysis

Step 1: Sorting	Compile a list of categories/sub-categories from the interview data sets. Enter into a coding matrix with categories/sub-categories as rows and sources as columns.
Step 2: Synthesis Coding	Code categories/sub-categories as discrete, convergent, dissonant and complementary.
Step 3: Group synthesis codes	Group and re-label the convergent and complementary synthesised codes.
Step 4: Apply frameworks	Group re-labelled synthesised codes based on the conceptual framework (Figure 8.2-2).
Step 5: Present conceptual diagrams of barriers and enablers to knowledge-sharing and collaboration	Present the categories from the data and conceptual framework diagrammatically into a model of barriers/enablers to knowledge-sharing and collaboration.

Steps 4 and 5 of the process draw upon the conceptual framework of barriers/enablers identified from the literature review (Figure 8.2-2).

Figure 8.2-2 - Conceptual framework of barriers/enablers to knowledge-sharing and collaboration from the literature review



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8.3 Findings - What is shared and what is duplicated in PPI across NIHR?

The snapshot from the document review revealed over half of the NIHRio in eight regions each had their own patient/public group. A smaller number had training resources, but this may have been an artefact of the reporting. There were some examples of NIHRio sharing training and patient groups regionally and beyond, and of joint working. Four regions did not document any such activity and in the remaining regions this was limited to one or two NIHRio sharing. More detailed resources data was collected in the RDS and locCRN (manifest analysis) and public member funding panel (latent analysis) interviews. These data are synthesised in the following section to determine what is duplicated and what is/could be shared.

8.3.1 Synthesis of RDS and locCRN resources and funding panel data

Synthesis and analysis of these resources and their potential utility for other NIHRio identified several opportunities for sharing and collaboration. Figure 8.3-1 provides an overview of how resources could be shared (Appendix O - Table of resources).

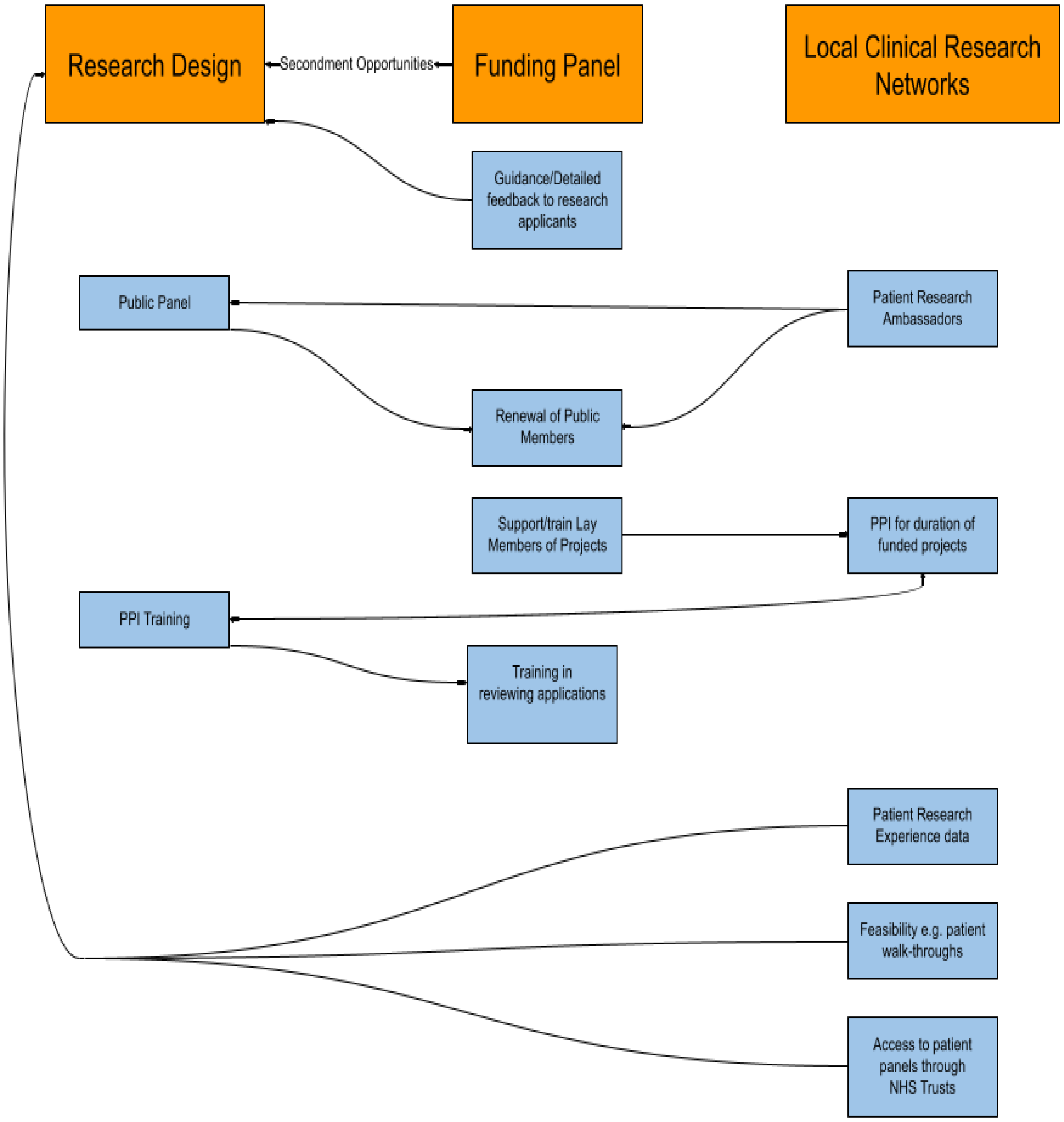
In the remainder of this section each resource will be discussed in terms of what could be shared *within* each infrastructure organisation nationally, i.e. RDSs sharing with other RDSs, and *across* NIHRio regionally and nationally.

Training

RDSs, locCRNs and funding programmes provided PPI training for researchers, staff and the public. The content ranged from the basic ‘What is PPI?’, and how to review research proposals to the more in-depth Building Research Partnerships Programme covering PPI at each stage of the research cycle.

In the RDS, a key role for PPI Leads was ensuring general and specialist advisors were fully trained in PPI and cognisant of all available resources. This training could be shared across the RDS, particularly as basic PPI advice is likely to be the same regardless of the region; it may also be of use to researchers and other NIHRio. Depending on the content of this training it could be offered to RDS clients when

Figure 8.3-1 – Opportunities for cross NIHR resource sharing



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they first consult the service. This may address the criticism from one informant that PPI can sometimes be an afterthought. One RDS had a video ‘What is PPI?’ which could be adopted by all RDSs perhaps with a list of FAQs. Although not everyone was positive about the Building Research Partnership training programme, because of the skills required to facilitate it and its scope, these could be convened in partnership with other NIHRio for those who wish to have a more in-depth induction to the research cycle and PPI. As the programme is designed for a professional and lay audience it could serve as training for researchers and public contributors including Patient Research Ambassadors. Delivering these workshops collaboratively would ensure enough attendees and share the burden of costs and organising.

Another RDS activity was lay training in reviewing funding applications, particularly the plain English summaries. This training could be invaluable to other NIHRio patient/public groups. It could be offered to public members of funding panels and external lay reviewers – or conversely NIHRio patient/public groups could attend the training that funding programmes provide to public contributors.

The RDS PPI Leads also spent time to ensure advisors were kept abreast of national and local PPI resources. A more efficient model would be to have a central repository of this information – with the facility for NIHR PPI staff to upload and update information - accessible to NIHRio and beyond. Awareness of these resources would increase the opportunities for NIHRio and other organisations to access the local PPI resources of different regions as had happened in some areas (Chapter 4).

Access to patient/public groups

A few RDSs had databases of regional PPI groups. Some locCRNs were constructing the same and others mentioned local NHS trusts were also doing so. The document review highlighted one particular region developing several ‘patient’ databases. These could be of use to NIHRio and to other organisations. This would be especially beneficial for researchers unable to access, for example, rare disease groups locally. Developing and maintaining these databases is time consuming and having one national database or linking regional ones would be a more efficient use of resources.

Resources to inform research design

The results of the locCRN Patient Research Experience Survey, where patient participants provide feedback on what worked well/not so well would be valuable to NIHRio involved in research design. Study Walk Throughs to elicit barriers to participation could be a useful component of feasibility prior to funding. The locCRNs conducted these once a study was funded and had ethical approval but could be carried out when a funding application is through to the second round of the research funding process. Formalising and evidencing this process could strengthen funding applications and help panels judge whether studies are burdensome for patient participants.

Regarding the public member panel role, it was difficult to understand why applicants did not receive the complete public contributor reviews when the PPI was sub-standard. Informants acknowledged the amount of work involved in developing a high-quality funding application and the pressures on clinician researchers. From the informants' accounts, providing detailed feedback on PPI was considered by the funding programme to be 'hand holding' but alternatively could be a way to educate researchers about PPI.

Events

There were opportunities for NIHRio to collaborate in locCRN events to promote research generally, specific projects or disease specific events. The RDS could promote opportunities for PPI, for example, identify potential members for their PPI groups and, at disease specific events, seek PPI in the design of studies under development and those interested in becoming lay co-applicants.

Resources to support PPI in funded projects

Resources to support lay members of research teams were held by some locCRNs, for example, attending trial steering committees. Public members of funding panels also highlighted the support they could offer research teams particularly those taking on the PPI role.

Opportunities for public contributors

For RDS PPI Groups and for public members of funding panels there did not appear to be a clear pathway or mechanism of progression to other parts of the NIHR or other funding panels. This was a lost opportunity. The RDS PPI Groups develop expertise in reviewing research studies over time, yet their membership of the group is time limited. Their expertise could benefit other NIHRio who have no access to such a group. As demonstrated in the interviews, the public member informants had a wealth of experience and expertise that could be useful to others in the NIHIR. Secondment opportunities for public contributors between the RDS/NIHRio and funding programmes could provide a flavour of other roles and create opportunities for involvement in different parts of the NIHR.

When discussing the formation of PPI groups, one of the locCRN informants pointed out that having too little to keep the group members occupied may impact on engagement. Affording the opportunities for PPI groups to support other NIHRio would ensure this does not happen. Patient Research Ambassadors (PRA) may also be interested in an NIHR public contributor role but as they are situated within NHS trusts their awareness of involvement opportunities in other organisations is unknown.

An on-line register where public contributors, including PRA, could sign up to learn about other opportunities regionally and nationally would be impactful. For the contributors it would ensure continuity in a PPI role, broaden their horizons for involvement and potentially create a shared community. For the NIHR it would be a way to retain this expertise and provide a source of willing public contributors to draw upon.

Cross NIHR PPI exchange.

Public contributors could benefit from the opportunity to experience involvement in other parts of NIHR, for example members of NIHRio patient/public groups shadow or observe a funding panel meeting. Informants who had experience of PPI as a co-applicant or as a lay member of a research project appeared to be more grounded in what was feasible, and the difficulties research teams encounter with PPI. Secondment opportunities, for public contributors, to different parts of NIHRio could provide valuable training and experience and enhance the conduct of their own role. The opportunity to engage with other parts of the NIHR in a PPI exchange initiative would give public members and lay external reviewers a greater awareness of the research development process.

8.4 Regional knowledge-sharing and collaboration - barriers and enablers

The document review (Chapter 4) revealed variation across the ten regions regarding collaboration. One unifying factor in most regions was the existence of a PPI-focused group, though in some regions only one or two NIHRio reported engagement with this group. In-depth information on the RDS and locCRN experiences of knowledge-sharing and collaboration was collected. In the next section these data are triangulated with the document review data to verify responses regarding cross-regional sharing and collaboration. This is followed by cross-case analyses of RDS and locCRN data first on the regional barriers/enablers to knowledge-sharing and collaboration.

8.4.1 Triangulation of document review, RDS and locCRN data on cross-regional sharing and collaboration

Triangulation was conducted on data from the seven (out of 10) RDS regions for which interview data was collected from both the RDS and the locCRN in their region.

The mapping data from the PPI annual reports and the RDS and locCRN interview data matched exceptionally well in relation to collaborations, resources and activities regionally. There were two exceptions. In the first the RDS and locCRN interview data matched but the connections were under-reported in the document review data (Table 8.4-1). As all three sets of data were from, or collected within, the same period (2017) this may have been an artefact of the level and detail of reporting.

Table 8.4-1 - Example of review, RDS and locCRN data matrix for one region

Source	**Code/categories for regional sharing and collaboration**
Document review	No reported connections between the RDS and locCRN One NIHRio reported discussions with RDS on more innovative PPI Reference to CRN collaboration with one other NIHRio
RDS interview	Collaborate with locCRN and CLAHRC through a regional PPI network 'made up of different parts of the NIHR infrastructure' (as part of INVOLVE-RDS contract)
locCRN interview	Collaborate with RDS and CLAHRC – and 'all the different NIHR organisations' - in a regional group.

The second revealed the mapping data to match with the RDS informant's reports of a lack of engagement from the locCRN, yet the locCRN informant said they met with several NIHRio regionally, including the RDS. However, they did express some difficulty in attending the meetings on a regular basis because of other commitments, but said the meetings lacked leadership and were not very productive. Because of this sporadic engagement and involvement in meetings the locCRN may have been omitted from the report data.

In summary, it can be concluded that most of the interview data provides a reliable representation of regional sharing and collaboration and was generally consistent with the infra-structure organisational mapping within the specific regions.

8.4.2 Cross-case analysis of regional barriers/enablers to knowledge-sharing and collaboration

The aim of this analysis was to build a picture of the main barriers/enablers to regional PPI knowledge-sharing and collaboration experienced by RDS and locCRN informants. In the conceptual framework these are divided into antecedent (or pre-condition) barriers/enablers to, and those that impact on the *act* of knowledge-sharing and collaboration. In the context of this project, the barriers/enablers to the latter, abstracted from the within-case analyses, related to the act of collaborative working (mainly the regional PPI groups) rather than of knowledge-sharing. Therefore, the recoded categories have been separated into two tables: one relating to antecedents or pre-conditions to knowledge-sharing and collaboration and the other only to the act of collaboration.

Antecedents to regional knowledge-sharing and collaboration

The combined RDS and locCRN list of antecedent barriers/enablers to regional knowledge-sharing and collaboration contained 14 categories. These were synthesis coded into six convergent (the same and could be collapsed into one), four discrete (identified in only one case but important to retain), and four complementary (the categories are different but linked). No dissonant categories (contradictory) were identified. In the next step, the convergent and complementary categories were merged into eight barriers/enablers and given a descriptive label (Table 8.4-2).

Table 8.4-2 – Process of cross-case analysis of antecedent barriers/enablers to regional knowledge sharing and collaboration from RDS and locCRN data

Barrier/enabler categories/sub-categories from RDS/locCRN within case analysis	**RDS**	**locCRN**	**Synthesis code**	**Merged and re-labelled enabler/barrier categories**
What can be shared – what is useful		✓	Discrete	Understand what can be shared/how can contribute
Silo working		✓	Convergent	Silo working
Others not sharing, engaging	✓		Convergent	
PPI un-coordinated regionally	✓		Complementary	Need to identify others in a PPI role
Need to identify NHS, NIHRio & university PPI		✓	Complementary	
Lack of awareness of who has a PPI role	✓		Complementary	
Job demands collaboration with non-NIHRio		✓	Complementary	
Part-time nature of PPI posts & fluidity of staff	✓		Convergent	Nature of PPI posts & fluidity of staff
Reasons specific to geography, logistics, PPI posts		✓	Convergent	
Culture of sharing & collaboration lacking		✓	Discrete	Culture of sharing & collaboration lacking
Duplication waste of resources	✓	✓	Convergent	Reduce duplication
Reduce duplication	✓	✓	Convergent	
Maximise resources, shared PPI posts		✓	Discrete	Work smarter, achieve high level objectives
Improve quality	✓		Discrete	Improve quality of PPI

These recoded barriers/enablers were checked against those generated from the within-case latent analysis for RDS and locCRN to ensure none of the key findings were lost.

In Figure 8.4-1 the eight re-labelled barriers/enablers have been ordered into those relating to the nature of the knowledge to be shared or contribution to be made, situational factors and individual motivation/demotivation, and the conceptual framework from Chapter 2 is applied. Explanatory text for the figure is given below.

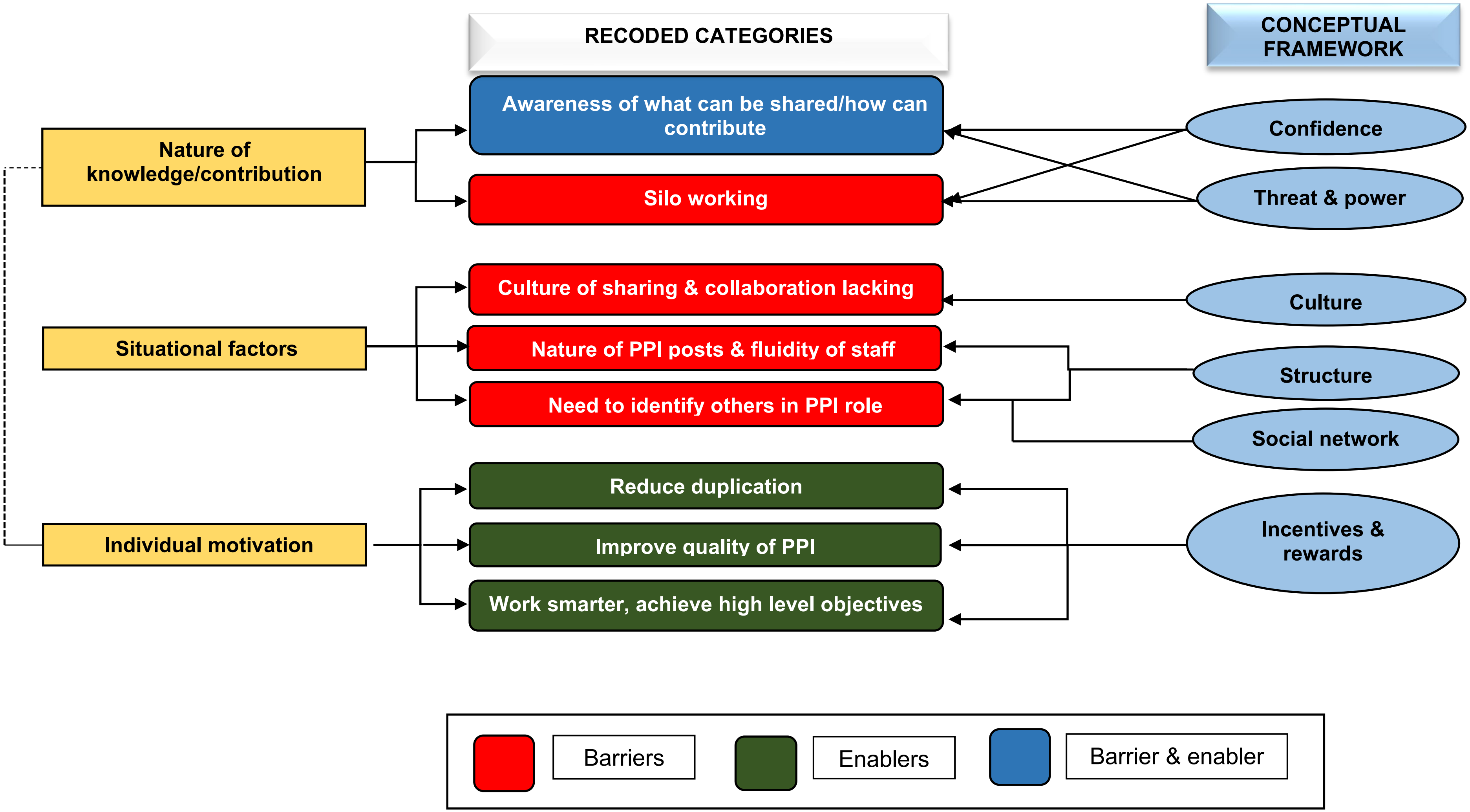
Nature of knowledge and contribution

Two categories relate to the nature of knowledge, and of the individual's contribution, as an antecedent of knowledge-sharing and collaboration. These are an understanding (or lack of understanding) of what one has to offer to others and silo working. The concepts of 'confidence' and 'threat and power' provide an extra dimension to understanding these two categories. As a barrier, not understanding what can be shared/how they can contribute could be attributable to a lack of confidence in a) realising *what* they have to offer and b) determining whether it is of *value* to others. This could also apply to the perceived value of others' knowledge/expertise. For example, as demonstrated in Chapter 7 one informant prioritised other commitments over attendance at regional PPI meetings as they questioned the value of those meetings. The barrier of individuals not appreciating the benefits of cross-partner working also fits within the 'individual motivation' antecedent.

The concept of threat and power may have come into play for those *who were aware* of what they had to share/contribute. As demonstrated in the literature review (Chapter 2), if workplace tacit knowledge is considered as power, and endows the individual with a competitive edge over others, sharing and collaboration can be perceived as a threat. Some informants did suggest that others perceived engaging in sharing and collaboration could lead to an appropriation of their initiative or patient group.

Silo-working was also given as reason for others' low level of engagement (Chapters 5 & 7) though it was difficult to ascertain what lay behind this behaviour. In the conceptual framework silo-working was identified as a barrier to collaboration, though it could also apply to knowledge-sharing. Lacking the confidence to share

Figure 8.4-1 - Model of antecedent barriers and enablers to sharing and collaboration



and the need to retain the power knowledge can give the holder, could lead to silo working. However, it could also be attributable to the situational and motivational factors described below. Silo working is a higher-level descriptor of a barrier and in many ways is unhelpful in understanding knowledge-sharing and collaboration – and identifying solutions - as it is potentially a symptom rather than a cause.

Situational factors

Three situational factors were identified that were said to impact upon engagement in sharing and collaboration: the lack of a sharing and collaborative culture (Chapter 5 & 7); the part-time nature of PPI posts, a heavy workload, and a high turnover of staff' and the need to identify others in a PPI role regionally as without this intelligence sharing and collaboration was hindered. Culture and structure were identified barriers/enablers from the conceptual framework. Organisational structure determines the nature of PPI posts and is responsible for a situation where NIHR PPI staff cannot identify their counterparts in the region. Social networks were an enabler from the conceptual framework and beyond the regional PPI groups there was no evidence of a PPI staff 'social network'. The existence of a wider social network may have helped to identify and connect with others in a PPI role.

The conceptual framework also included leadership as a barrier/enabler. Few of the informants mentioned support from their own infrastructure organisation in their attempts at cross-regional working. With the advent of the INVOLVE/RDS partnership RDS regions had the support of INVOLVE staff though some informants commented these individuals had insufficient time to do this (Chapter 5).

Individual motivation

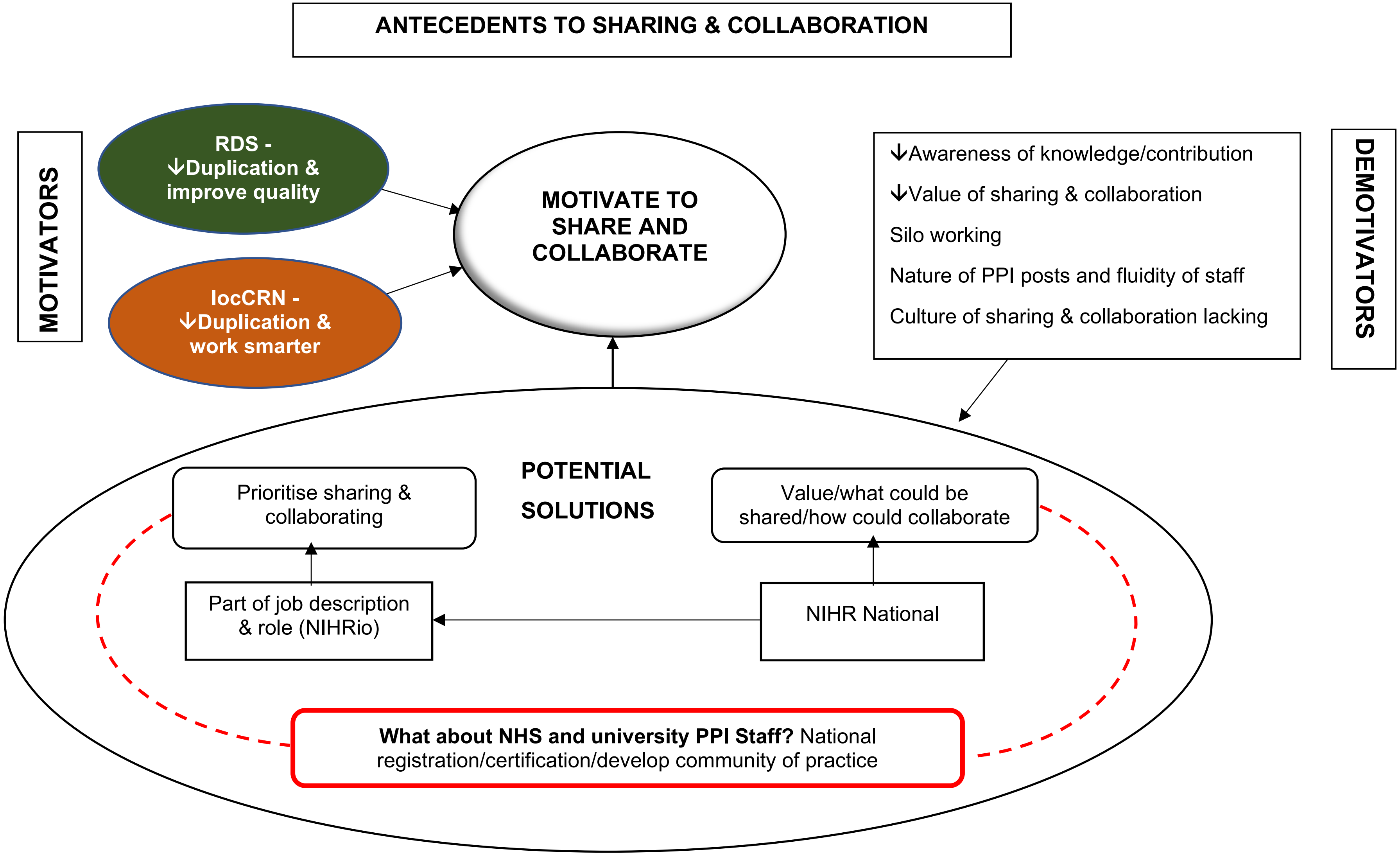
Individual motivation to share and collaborate came across strongly in the RDS and locCRN data. The intrinsic (such as increasing their chances of promotion) or extrinsic (personal financial gain) incentives/rewards, as defined in the conceptual framework, were not mentioned by informants. In the context of this project the incentive was the desire to reduce duplication of PPI activities. The RDSs were also driven by the wish to improve the quality of PPI regionally and locCRNs for pragmatic reasons. These reasons were to maximise scarce resources and overcome problems such as recruiting to vacant PPI posts. A key locCRN incentive was to achieve their high-level objectives.

What was less evident from the data was whether informants felt that others in a PPI role were motivated to share and collaborate. The silo-working reported by informants could be due to the nature of knowledge/collaboration as reported above, a lack of incentives, the culture, or the nature of PPI posts. This relates also to the nature of knowledge, its perceived value to individuals, an appreciation of what can be shared, and concepts of confidence and threat and power.

Solutions – facilitating the antecedents to knowledge-sharing and collaboration

One solution to engender the antecedents to knowledge-sharing and collaboration would be for NIHR national/the CCs to prioritise and emphasise the value and benefits of sharing and collaboration (Figure 8.4-2). NIHR PPI job descriptions should specify sharing and collaboration as essential activities. Guidance on effective sharing and collaboration, examples and suggestions of what could be. shared and of collaborative initiatives would be beneficial. Due to the size of some regions involving all NIHR PPI staff in cross-regional group meetings may not be feasible and, as demonstrated in the data, those in NHS trusts, universities and charities are more difficult to reach and encourage to engage. More innovative ways of harnessing the expertise and enabling the involvement of all PPI staff in collaborative ventures are needed. Some form of community of practice with requisite benefits and accreditation would be beneficial. This could be a first step to identify the knowledge individuals possess that could be shared, and what they can contribute, and determine and agree key areas for collaboration.

Figure 8.4-2 – Proposed solutions to enabling antecedents to sharing and collaboration



ANTECEDENTS TO SHARING & COLLABORATION

MOTIVATORS

RDS - ↓Duplication & improve quality

locCRN - ↓Duplication & work smarter

MOTIVATE TO SHARE AND COLLABORATE

- ↓Awareness of knowledge/contribution
- ↓Value of sharing & collaboration
- Silo working
- Nature of PPI posts and fluidity of staff
- Culture of sharing & collaboration lacking

DEMOTIVATORS

POTENTIAL SOLUTIONS

Prioritise sharing & collaborating

Part of job description & role (NIHRio)

Value/what could be shared/how could collaborate

NIHR National

What about NHS and university PPI Staff? National registration/certification/develop community of practice

Barriers/enablers to the act of regional collaboration

The list of barriers/enablers to the act of regional collaboration – namely those that came into play for those who are motivated to share and collaborate - from the RDS and locCRN case study data contained 14 categories. The same process was followed as with the antecedents. The categories were coded into six convergent, eight discrete, and one complementary. No dissonant categories were identified. After coding, these were merged where appropriate and re-labelled into six barriers/enablers (Table 8.4-3).

Table 8.4-3 - Process of cross-case analysis of barriers/enablers to the act of collaboration regionally

Barrier/enabler categories/sub-categories from RDS/locCRN within case analysis	**RDS**	**CRN**	**Synthesis code**	**Merged and re-labelled enabler/barrier categories**
Relinquishing control of group	✓		Discrete	Relinquishing control of group
Are groups the best mode of sharing and collaborating	✓		Complementary	Appropriate mechanisms of sharing and collaboration
What is PPI in research delivery	✓		Convergent	Understanding PPI in research delivery
PPI in research delivery unclear		✓	Convergent	
Understanding each other's roles		✓	Discrete	Understanding each other's roles
Different ways of working are a drawback		✓	Discrete	Differences in PPI remit and working practices
Different remits can be liberating		✓	Discrete	
Others overreaching remit	✓		Convergent	
Different remits can impact on collaboration negatively		✓	Convergent	
Important to be aware of remits		✓	Discrete	
Not all engaging equally	✓		Convergent	Not all engaging
Same core people who engage		✓	Convergent	
Low level of trust from others		✓	Discrete	Lack of trust
Issues with reciprocity		✓	Discrete	Issues with reciprocity

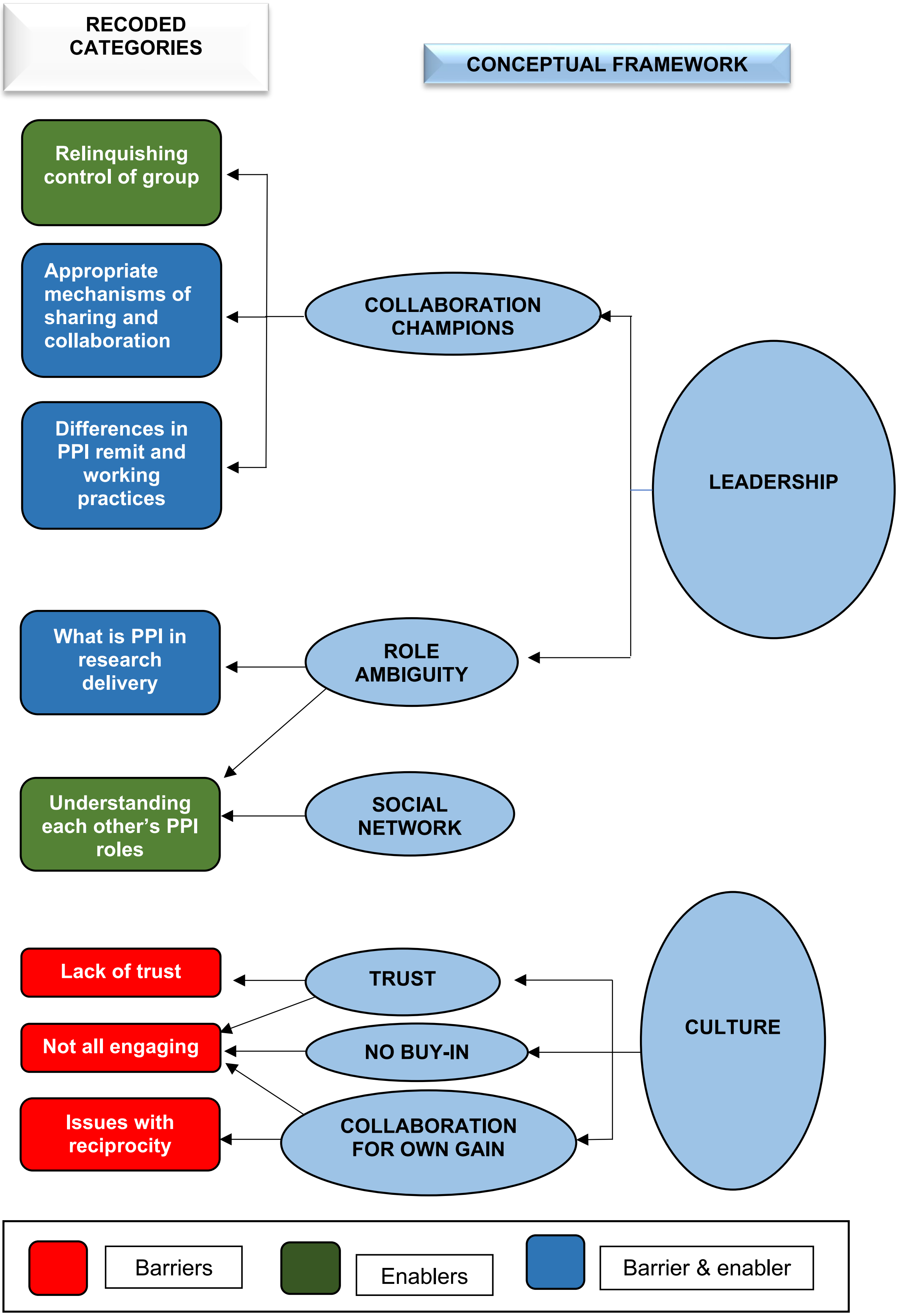
Again, the recoded barriers/enablers were checked against those generated from the within-case latent analysis for RDS and locCRN to ensure none of the key findings were lost.

Although there was little published regarding the barriers/enablers to intra-organisational collaboration (Chapter 2), 11 factors were identified and included in the conceptual framework, eight of which were relevant to the data. These concepts and the corresponding data are presented as a model of barriers/enablers to regional sharing and collaboration in Figure 8.4-3. Each concept will be discussed in turn in the following sub-sections.

Collaboration champions

Both RDS and locCRN informants commented that the regional groups were slow to progress, or had not yet progressed, to collaboration. Informants were not able to explain why this might be, but three key factors were identified from the data. The first was relinquishing control of the group. This was cited as a difficulty by one informant who had re-purposed an existing group to one that was cross-regional and collaborative. Related to this, in the interviews the way some informants described group interactions indicated these did not appear to be collaborative ventures. There was little in the data to indicate that any of the PPI group members undertook a process to agree upon shared goals or mutual benefits. The second was whether the group meeting was an appropriate mechanism for regional sharing and collaboration.

Figure 8.4-3 – Model of barriers and enablers to collaboration



Although intuitively group meetings appear a viable option to facilitate sharing and collaboration, particularly if a regional group already exists, membership may be restricted in the larger regions with more PPI staff and ensuring the meeting is scheduled for a time suitable for everyone could be a challenge. Finally, the different PPI remits (involved in the design and/or delivery) were cited by some as a barrier and others as an enabler. Some thought the different remits hindered collaboration, but others expressed more positive views. It was said that these differences could facilitate cross-regional working as each NIHRio had their own PPI space and this reduced the likelihood of encroaching on the work of others. Different ways of working, for example the types of patients/public PPI staff engage with, was also cited as a drawback to collaboration. As might be expected, these three more granular barriers/enablers are not represented in the conceptual framework. However, all three point to a need for support to collaborate: to learn how to work with the differences across the NIHRio and to foster a collaborative environment, and guidance on alternative modes of collaboration. Collaboration champions from the conceptual framework has been added to the model, as someone in this role could provide the necessary support. The concept of leadership - defined as management support (ensuring staff have the time and resources) for collaboration - has been added as an overarching potential barrier/enabler to the provision of a collaboration champion.

Role ambiguity

Everyone was clear about the nature of PPI in research design yet acknowledged it was more complex in a research delivery context when studies are funded and have ethical approval and making changes is problematic. Both RDS and locCRN informants talked about the lack of clarity regarding the nature of PPI in research delivery. An outcome of this lack of clarity was not fully understanding where one fits in relation to others for PPI in the research pathway. This was said to present a barrier to individuals contributing to a shared venture but could also be an antecedent to sharing and collaboration.

There was also evidence that some locCRN misunderstood the role of the RDS, stating they thought the RDS should be involved in the early stages of study design, which they are (Chapter 7). This second factor links to the concept of role ambiguity as a barrier from the framework, where not understanding each other's roles impedes collaboration and leads to those involved feeling isolated. Social networks were cited as enablers in the conceptual framework. The existence of such a network of NIHR PPI could facilitate contact between relevant staff and provide the opportunity to learn about each other's roles.

Based on the data, the concept of role ambiguity from the framework can be broadened to encompass two other areas of ambiguity, of understanding the place of PPI in the research pathway and of a member's role as part of the collaborative. These two areas of ambiguity are intertwined as it would be difficult to understand your role and PPI contribution within a collaboration if you do not fully understand PPI in your own workplace. The overarching concept of leadership has also been applied as NIHR national/CCs need to clarify the place and scope of PPI in research delivery to support those in an NIHR PPI role.

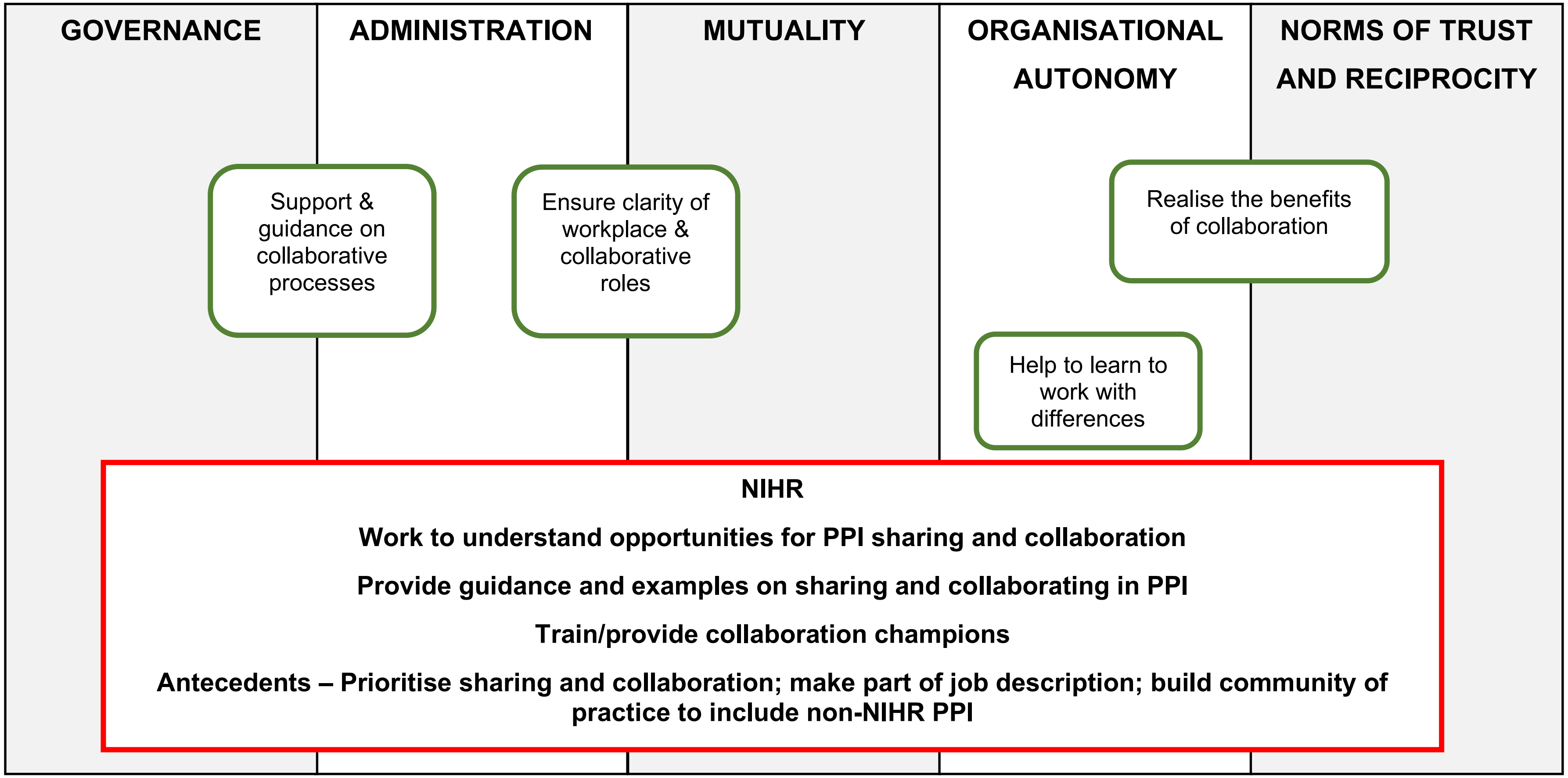
No buy-in, trust and collaboration for own gain

Not engaging, lack of trust and issues with reciprocity were the recoded barriers to collaboration. The conceptual framework has four related concepts. One of these, silo-working, has not been added to the model for the reasons mentioned earlier, that it does not explain the behaviour. The concept of 'Trust' maps directly to the 'lack of trust' barrier identified from the data which was more evident from the locCRN informants' accounts of their experiences of trying to collaborate. Again, with locCRN informants, their attempts to collaborate with NHS trust PPI staff, could be perceived as seeking to do so for their own gain – though as that was the route to deliver on the PPIE objectives they had little choice. The reciprocity of financial incentives in this case was not appreciated. This maps to the 'Collaboration for own gain' concept. The third related concept of 'Buy-in' is mapped against the recoded category 'not engaging' (which again is descriptive rather than explanatory) though this behaviour could also be attributable to a lack of trust and collaborating for their own gain. The three concepts of ‘No buy-in’, ‘Trust’ and ‘Collaboration for own gain’ suggest issues related to an overarching concept of culture, that NIHR does not have a fully collaborative culture.

Solutions – ensuring key processes in collaboration are implemented

As indicated in the literature review (Chapter 2), successful collaboration requires the antecedents (described earlier in this chapter) and specific processes in place. Although inter- rather than intra-organisational, a review of public sector collaboration suggests five processual dimensions of governance, administration, mutuality, organisational autonomy and norms of trust and reciprocity to ensure successful collaboration.[119] These highlight the complexity of facilitating collaborative working and could explain why the regional PPI groups have struggled to move from sharing to collaboration (Figure 8.4-4). Within the administration dimension collaborative roles should be agreed but the data highlight a potentially more pervasive issue of informants not understanding each other’s (or sometimes their own) PPI role in the research pathway. This lack of understanding could inhibit the identification of mutual benefits (mutuality) of collaboration and the shared or different interests. In relation to organisational autonomy, although it would be expected that those in a PPI role have a shared interest in ensuring the patient/public voice is considered in all stages of the research they also have their own role to fulfil and, particularly for the locCRN, objectives to achieve on which they are measured. The differences between NIHRio were often mentioned and regional groups need support to learn how to work with these differences. Realising the benefits of collaboration will also help those involved to deal with any tension created by organisational autonomy but also establish the norms of trust and reciprocity. These norms are also antecedents to sharing and collaboration but may also have been the reason why some PPI staff had initially engaged in groups and then their involvement had tailed off. All these issues point to the need for support and advice from NIHR national or the CCs on the following. First, work is needed to understand

Figure 8.4-4 – Ways to support regional collaborative working



NIHR

Work to understand opportunities for PPI sharing and collaboration

Provide guidance and examples on sharing and collaborating in PPI

Train/provide collaboration champions

Antecedents – Prioritise sharing and collaboration; make part of job description; build community of practice to include non-NIHR PPI

the opportunities and benefits for those in a PPI role of sharing and collaboration. Once the opportunities and benefits are clear, guidance and examples of what could be achieved should be shared. provided. This guidance could be in the form of training or offering collaboration champions to support cross-regional working. To ensure the antecedents to sharing and collaboration (including continued engagement in collaborative ventures) this needs to be prioritised and formalised; for example, be part of the job descriptions of NIHRio PPI staff. To attract those in NHS trusts and charities, a community of practice could be created with the input of those in a PPI role in the different settings to ensure it meets the needs of those involved.

This section has provided a picture of the combined RDS and locCRN barriers/enablers to regional knowledge-sharing and collaboration and potential solutions. In the following section the barriers/enablers to *national* knowledge-sharing and collaboration are explored for the RDS and locCRN.

8.5 National knowledge-sharing and collaboration - barriers and enablers

Table 8.5-1 lists 14 categories from the data relating to barriers/enablers to national sharing and collaboration. Except for two categories (1 & 2 in the table), these relate to PPI national fora and communications. The first exception relates to sharing across neighbouring locCRNs. Although some locCRN informants said collaborating with a neighbouring locCRN was a future goal only one had done so. In this case, collaboration was driven by resource issues and fits with the antecedents framework (Figure 8.4-1) specifically with the need to work smarter and maximise resources. The second was the utility of other locCRNs sharing successful PPI initiatives as there was often little likelihood of it working in other regions because of the difference in size, for example. Although this category is about sharing it fits with the recoded ‘Differences’ barrier/enabler from the collaboration framework (Figure 8.4-3). In the context of national sharing, someone with the requisite skills, perhaps a collaboration champion, could advise or support locCRN PPI staff to consider what from their initiative might be pertinent to other regions and the key points of learning that are useful to share.

Table 8.5-1 – Process of cross-case analysis of barriers/enablers to national sharing and collaboration

Barrier/enabler categories/sub-categories from RDS/locCRN within case analysis	**RDS**	**locCRN**	**Synthesis code**	**Merged and re-labelled enabler/barrier categories**
Sharing with neighbouring locCRNs to maximise resources		✓	Discrete	Work smarter, achieve high level objectives
locCRN initiatives are not always suitable for other regions		✓	Discrete	Differences – remit, working practices
PPI National leads meetings				
PPI leads meeting no longer focused on sharing and collaboration	✓		Complementary	National fora do not enable sharing and collaboration
PPI leads meeting does not drive sharing and collaboration		✓	Complementary	
Difficult for new RDS PPI staff in national forum	✓		Discrete	
Communications				
One-NIHR as an intervention to encourage sharing and collaboration	✓		Convergent	NIHR campaign messages not always clear
Interpretation of One NIHR as a message to collaborate		✓	Convergent	
How national communications are interpretated at a local level	✓		Convergent	
Disillusioned with campaign messages	✓		Convergent	Disillusioned with NIHR campaign messages
Staff jaded with campaign messages and changes		✓	Convergent	
Inconsistent messages	✓		Convergent	Communications from CC can be inconsistent or unhelpful
Unhelpful messages		✓	Convergent	
Communications not conducive to sharing		✓	Discrete	Communications not conducive to sharing
Lack of understanding of INVOLVE/RDS Partnership	✓		Discrete	Lack of understanding of INVOLVE/RDS Partnership

The 12 remaining barriers/enablers were ordered into the formal mechanisms namely the PPI national meetings and communications from the CC. As demonstrated in Chapters 5 and 7, these were enablers for the majority of RDS and locCRN informants. However, there were some dissenting voices which indicates there may be room for improvement. As before, the categories were then coded using the synthesis codes and then merged where appropriate and re-labelled. With the application of the conceptual framework barriers/enablers could be encompassed within the two higher level concepts of 'Culture' and 'Leadership'.

These are presented in Figure 8.5-1 and discussed in detail in the following sections structured by the three mechanisms for sharing and collaboration.

PPI National leads meetings

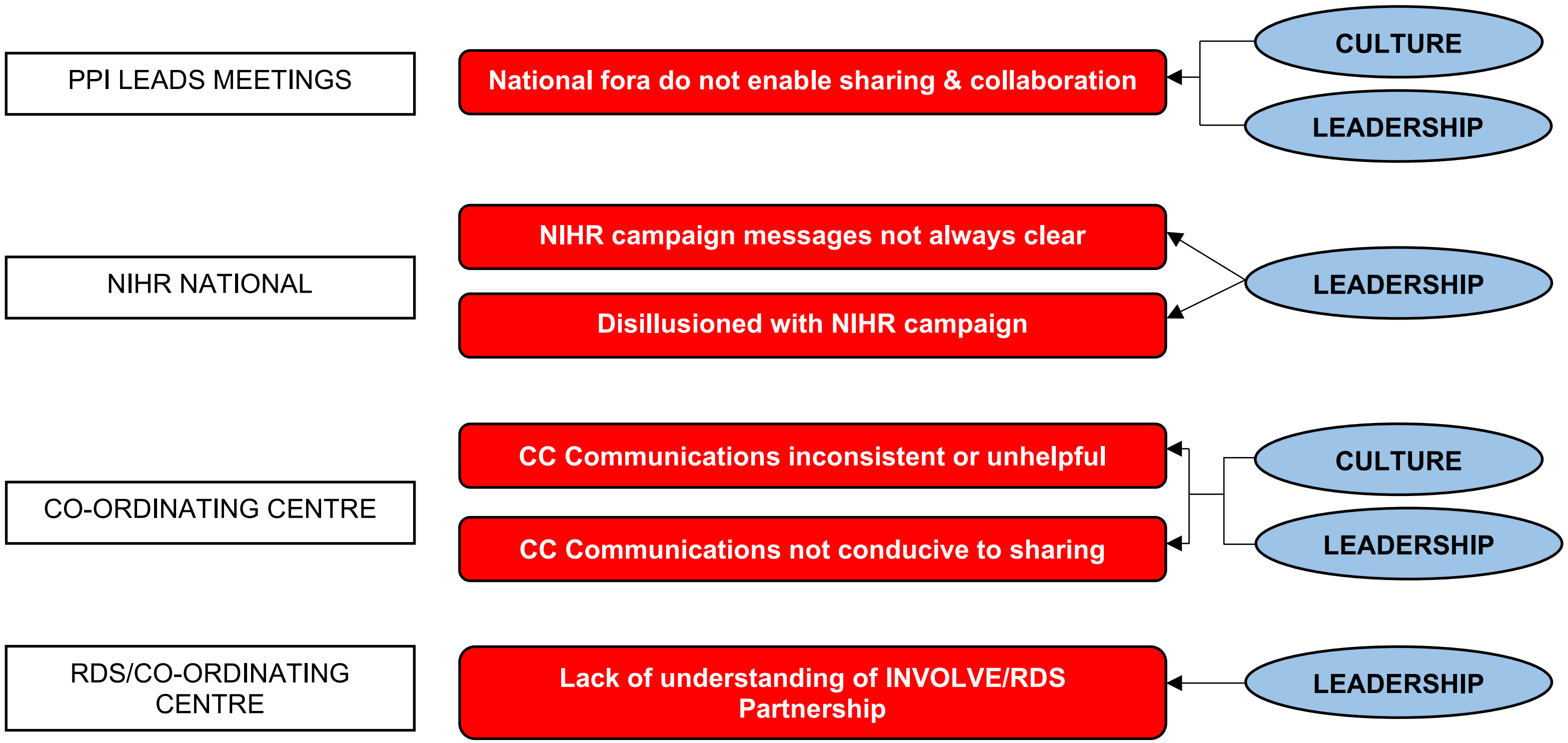
Some informants did not consider the respective RDS and locCRN national PPI meetings played a role in facilitating or driving sharing and collaboration. New members did not feel part of the group. There did not appear to be a mechanism for the other PPI team members to contribute to, or be involved in, these meetings and they were dependent upon the PPI leads to cascade information or outcomes from the meetings. This lack of opportunity for non-attendees to be involved nationally, and the claims that these fora could do more to promote sharing and collaboration, suggests the culture is not truly collaborative. Achieving a collaborative culture is complex and will be discussed at greater length in Chapter 9.

The findings also suggest leadership, in terms of how the meetings are structured and the processes followed, may be a barrier/enabler. Leadership support would be needed to adopt the processes demonstrated in the previous section for successful collaboration and enlist the help of a collaboration champion to ensure mutuality, trust and reciprocity.

NIHR national communications

There is no doubt that NIHR campaigns such as ‘OK to ask’, ‘I am research’ and ‘One NIHR’ were well intended. One NIHR was an attempt to present a single NIHR to internal and external stakeholders yet regionally the campaign was interpreted quite differently. Some RDS and locCRN informants were disillusioned with NIHR

Figure 8.5-1 - Application of conceptual framework to barriers and enablers to national sharing and collaboration



campaigns and confused about changes particularly whether new ones launched superseded others. An example of NIHR changes from the second round of locCRN interviews is one informant said staff were asked not to use the One NIHR slogan on the grounds that it suggested the NIHR was not ‘One'; and if it had been ‘One’ the campaign would have been unnecessary.

It was difficult to disentangle why One NIHR had been interpreted as a call to share and work more collaboratively but this and the fact that some staff are jaded with the messages, suggests a need to evaluate how campaigns are received. In the conceptual framework these issues suggest ‘Leadership’ in the context of national communications is a barrier/enabler that can impact on effective communication.

Communications from the co-ordinating centres

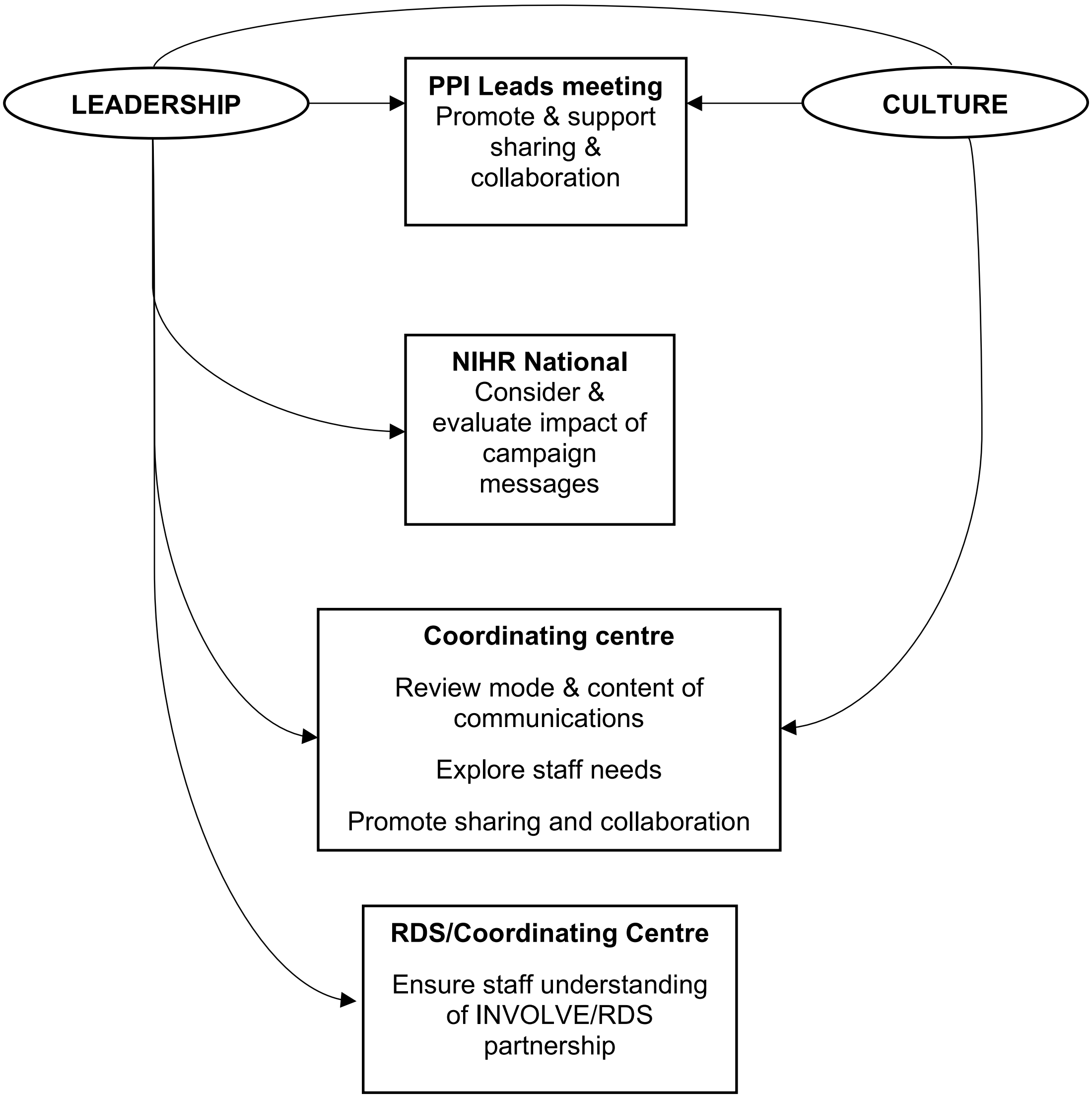
The issues with communications from the CC suggest barriers/enablers reflective of the culture and leadership. Communications from the CRNCC, either ad hoc or in the form of newsletters, were not always useful and thought to fall short of the mark. It was said the newsletters could be instrumental in sharing experiences of how the different locCRNs were tackling the PPI high level objectives but this did not happen. Also, ad hoc communications meant to encourage collaborative working could lead to staff being disgruntled when not handled sensitively (Chapters 5 & 7).

From the RDS perspective, informants did not fully understand the INVOLVE/RDS partnership, particularly its longer-term aim. This may have hindered regional sharing and collaboration which was a key goal for the partnership. In this context leadership was a barrier as, from the informants’ accounts, little or nothing was done to ensure RDS staff fully understood the purpose of the partnership.

Solutions – leadership role and culture in promoting sharing and collaboration

Figure 8.5-2 illustrates ways to support national knowledge-sharing and collaboration within the current mechanisms. Those who facilitate the national PPI Leads meetings should promote and support sharing and collaboration, implementing processes to ensure effective collaboration. NIHR national should consider how campaigns are interpreted at a regional level and their impact on individuals and working practices. Regarding communications, the findings suggest the need for a review by the CRNCC. To ensure the different forms of communications enhance cross-regional and national working, they should explore what information PPI staff (at all levels) need and what would be helpful. At the same time, they should avoid inconsistent messages that only serve to confuse PPI staff. Finally, RDS/CC should ensure all RDS PPI staff understand the longer-term goals of the INVOLVE/RDS partnership. As suggested earlier (Chapter 5) RDS PPI staff could be involved in and contribute to higher level discussions about the profile and progression of the partnership.

Figure 8.5-2 – Ways to improve national knowledge-sharing and collaboration



8.6 Reflection and discussion

This chapter has verified the RDS and locCRN interview data regarding sharing and collaborative activities regionally. It has also provided a picture of the barriers and enablers to knowledge-sharing and collaboration at a regional and national level, and the opportunities for sharing resources.

Before moving to summarise the findings, I would like to add some reflections on my own experience of cross-regional PPI working. Through my own involvement (from January 2015 – June 2017) with a regional PPI group we experienced the same challenges to sharing and collaboration as described in this chapter. This group was established in January 2015 motivated by a need to map regional PPI as the public and researchers found it difficult to understand and navigate PPI/E across the different organisations. From April 2016, with the advent of the INVOLVE/RDS partnership, the chair and founder of the group suggested the RDS take on the role of leading it.

Similar to the findings of this project, this group also experienced a lack of engagement and attendance at the meetings waned over time. However, in our experience this was a particular issue with those in a full-time role and therefore unlikely to be attributable to the part time nature of PPI posts. There are several explanations for this, including a loss of group momentum, the ownership of the group was not shared, the different remits for PPI and a lack of understanding of these, and the group did not have a clear purpose in terms of collaboration.

Maintaining momentum of the group was difficult. Meetings were quarterly and months could pass before action points were addressed. This was exacerbated if key members missed meetings, and possibly led to some members losing interest. This group was formed without jointly agreeing governance and administrative structures. Instilling a feeling of shared ownership and control between all members of the group was difficult. On reflection, the perception that the group was the province of the RDS could have been a barrier to the engagement of others.

The different remits, and a lack of understanding of what these are for each NIHRio, were a challenge. This became apparent when trying to collate and categorise the resources of each NIHRio and when sharing initiatives during the group meetings. There needed to be a way of keeping members engaged, and for some that appeared to be the chance to share at the meeting – beyond the round table updates - what they were doing. However, it occurred to me after one meeting that some members did not have a clear understanding of the role of others from different organisations, or perhaps they did but merely wanted to showcase their initiatives and did not take the time to talk about their wider relevance or potential benefit for others in the group. In addition, the group was so heavily focused on mapping regional PPI that cross cutting issues, or even issues that individual members may have had, were not discussed. This latter point illustrates that mutuality, what benefits group membership brings to individuals, was not appreciated.

Finally, and most importantly the group did not have a clear purpose, particularly not a collaborative one. The mapping exercise – a key reason for forming the group and a goal for the INVOLVE/RDS partnership - was presented as an end rather than a means to an end.

On reflection, apart from the processes outlined in this chapter, there are some measures we could have introduced to improve engagement and how the group functioned. Forming a sub-group of those who had the time and inclination to progress the agenda or work in parallel may have been a more dynamic way to engage members. Processes such as an action log, shared ‘live’ updates recorded in a shared space may have helped. Mapping regional PPI was quite complicated and direction from INVOLVE, even in relation to practical issues such as how to collate and present resources, would have been welcomed. Collecting that information to satisfy the INVOLVE/RDS partnership or what by the end was a rather nebulous goal of improving navigation of the different organisations for patients, the public and researchers, was bound to be a difficult process. The fact that the group did not have a purpose or a point to progress it to one of joint working was a major barrier to collaborative regional PPI working. Its focus was on reporting back and showcasing rather than embarking on any collaborative activities. Perhaps in the period of my involvement it was too early to expect collaboration and the group had to establish a sharing culture before it progressed to a collaborative one. However, I believe that with some guidance, from those who were promoting regional PPI/E collaboration, this could have been achieved.

Solutions

There are six key take-home messages from this chapter.

1. The NIHR has rich PPI resources and more could be shared. A national repository of physical resources such as training videos and guidelines should be available to those in NIHR and beyond. This could free up NIHR staff time to conduct innovative PPI and address the PPI inadequacies of those who do not consult services when developing funding applications.

2. A register of public contributors – including those in trusts, universities and charities - would provide the opportunities for individuals to be involved in other ventures. This register should go beyond those involved in NIHR activities to ideally include everyone who has had experience in a PPI role.

3. Secondment for public contributors to other parts of NIHR could be beneficial in a several ways. A cross NIHR PPI exchange would enable those a public contributor role (including patient research ambassadors) to experience and learn about other opportunities and would be of benefit to those in the role and to NIHR more broadly.

4. The NIHR culture does not appear to be one of knowledge-sharing and collaboration. To foster such a culture, individuals must: realise the benefits of sharing and collaboration; and understand what knowledge and expertise they hold and could share, and what they have to contribute to a collaboration.

Exemplars and suggestions of collaborative ventures could be provided. Communications and fora, such as the national PPI meetings, should be reviewed to ensure sharing and collaboration is at the core and that these mechanisms meet the needs of PPI staff.

5. Effective collaboration will not happen serendipitously. Simply setting up a group and meeting will not lead to collaborative working and as Thomson states ‘Although information sharing is necessary for collaboration, it is not sufficient for it to thrive. Without mutual benefits, information sharing will not lead to collaboration’ (p27).[119] Other key processes were governance and administration and both may have been problematic in established groups that were trying to move to more collaborative working but were tied to the previous practices. If regional PPI co-ordination and collaboration are the goals, then support and guidance from NIHR national/co-ordinating centre is needed.

6. The creation of a community of practice of PPI staff could bring those in a PPI staff role (including universities, NHS and charities) and help to connect individuals and facilitate collaborative working. If there were greater awareness of the resources each NIHRio holds and an understanding of each other’s roles this could facilitate cross-regional PPI collaboration. One example is the Patient Research Experience Survey run by the locCRN. The locCRN may consider this as a performance metric rather than a way to improve research design; and the RDS may not understand or even be aware this resource exists.

In the next chapter these, and some of the key concepts, such as changing organisational culture and developing communities of practice will be discussed drawing upon the relevant literature.

Chapter 9: Discussion & conclusion

The aim of this project was twofold. The first to highlight areas for improvement in, and potential solutions to, regional and national PPI knowledge-sharing and collaboration through the identification of barriers/enablers. In the context of this project, knowledge refers to explicit and tacit (experiential) knowledge. Intra-organisational collaboration is defined as:

> *'when people within an organization work together to achieve common goals through communicating and sharing strategies, knowledge, resources, and information' (page 323).*[130]

The second aim was to identify opportunities for sharing PPI resources across the infrastructure organisations involved in research design, funding and delivery, and determine whether a streamlined NIHR PPI model is feasible.

The cases included in this project possessed a rich vein of physical and human PPI resources. However, not a great deal was shared with others regionally or nationally within their own infrastructure organisations, and there was duplication of activities. Opportunities to harness the skills and experience of public contributors were not acted upon. There were some examples of PPI staff making connections through regional groups. However, from the informant accounts, in these groups most *reported* PPI activities rather than sharing knowledge *per se* and there was little evidence of joint working. Some of those with a cross-regional PPI group struggled to progress to collaboration.

To address the research question 'What are the barriers/enablers to regional and national knowledge-sharing and collaboration in NIHR PPI?', this chapter begins with a brief overview of the amended conceptual framework followed by a discussion of the barriers/enablers under the umbrella concepts of 'organisational culture' and 'leadership/management' in relation to the literature. To address the second research question, the elements of a streamlined model of PPI from research design to delivery are proposed in Section 9.2. This is followed by a summary including limitations of the project, contribution to knowledge and areas for future research. The chapter concludes with key recommendations.

9.1 Barriers and enablers to NIHR PPI knowledge-sharing and collaboration regionally and nationally

Following the cross-case analyses the conceptual framework derived from the public sector literature has been refined into an over-arching framework that encompasses knowledge-sharing and collaboration at both regional and national levels (Figure 9.1-1). This framework is divided into individual and organisational barriers/enablers that impact on the antecedents to, and the act of, knowledge-sharing and collaboration. Knowledge-sharing and collaboration were merged as the project findings suggest the antecedents (primarily individual) are the same for both behaviours. Apart from ‘collaboration champions’ the remaining organisational barriers/enablers apply to knowledge-sharing and collaboration. Two key higher-level barriers/enablers of organisational culture and leadership subsume lower-level barriers/enablers. New reciprocal concepts that may underlie organisational and culture have been added as described in Section 9.1.3.

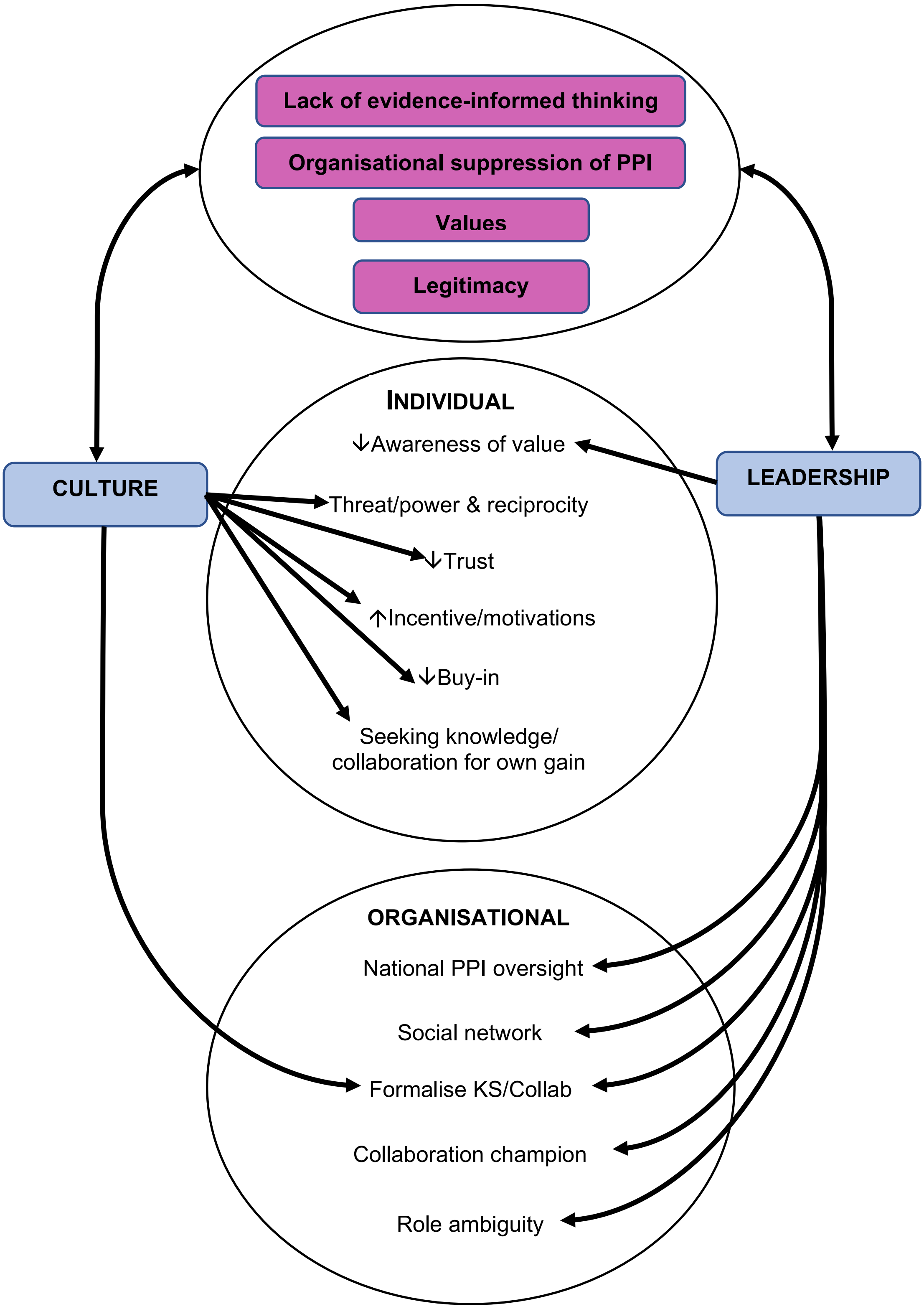
The barriers/enablers from the revised framework are discussed in the subsequent sections drawing upon the public sector intra-organisational knowledge-sharing and collaboration literature.

9.1.1 Organisational culture

<u>Individual barriers/enablers</u>

Six individual barriers/enablers were identified that could explain the lack of engagement in shared ventures and silo-working of others in a PPI role. Five of these are considered part of the NIHR workplace culture. The barriers/enablers are threat/power and reciprocity, trust, incentives/motivation, buy-in and collaboration for own gain.

Figure 9.1-1 – Revised conceptual framework of individual and organisational barriers/enablers to intra-organisational knowledge-sharing and collaboration at a regional and national level



Trust, threat, and reciprocity

Barriers such as a lack of trust in the knowledge recipient and the threat of sharing and collaboration were identified when informants talked about their experiences of trying to engage with those in a PPI role. This is consistent with the literature where a lack of trust is a recurrent barrier to knowledge-sharing in public sector organisations[118, 174] and when there is trust between parties this impacts positively on knowledge-sharing behaviour [126, 143, 149, 152, 154, 156], intentions and attitudes.[159] Where trust had no impact on knowledge-sharing it was surmised that this was related to the value individuals place on the knowledge and the risk of sharing.[142]

Although the studies included in the literature review do not specify the type of tacit knowledge, the reported risks of sharing were the loss of standing or value of the individual within the organisation [136, 139] and damage reputationally if the knowledge is not considered of worth.[173] Threat in the context of the current project is possibly more nuanced where others were perceived to be reluctant to share the resources (patient groups, initiatives) they had worked hard to build. Without additional data from these individuals, it is difficult to surmise their reasons. Possibly, as Basit-Memon found, the threat is that their hard work will not be acknowledged and others may use the resource to their own advantage.[140]

As shown in this project the sharing was not always reciprocal, and this could have impacted on the willingness of others to engage. This may be associated with the concept of low individual appreciation of what they have of value to share, but also points to a need to explore and understand what the other party could or would like to gain from sharing and collaboration. Only two of the studies included in the review explored reciprocity as a barrier/enabler to knowledge-sharing and their findings were contradictory.[137, 142] Reciprocity was not a determinant of knowledge-sharing for professional to service/maintenance university employees[142] yet was in management-level government employees who looked for willingness to reciprocate before sharing.[137] This may have been attributable to the range of different occupations of the respondents, particularly in the first study. In the context of this project, the informants were a homogeneous group in the sense that they all had a remit for PPI. However, the locCRN informants ranged in role and seniority and, although there was no evidence that this impacted on their own willingness to share, those from other organisations who were more junior may not have considered it a reciprocal relationship and thought they would receive little in return.

Incentive/motivation

Realisation of the potential value and benefit of knowledge-sharing and collaboration is part of motivation, an antecedent to knowledge-sharing[299] and collaboration (acknowledging mutual benefits).[119] Potential benefits are extrinsic and intrinsic incentives/rewards, though the literature review revealed variation in the impact of these on knowledge-sharing across the settings. Incentives/rewards such as remuneration and opportunities for promotion (within a PPI role) did not appear to be available to the informants in this project. In fact, the main driver of knowledge-sharing and collaboration was to reduce duplication of activities, and there was little mention of the value or benefit beyond that. It was possible that informants, and others who were expected to share and collaborate, did not perceive any direct personal or organisational benefit from doing so. This finding broadly supports those of other public sector studies linking knowledge-sharing[134, 141, 158] and collaboration with individuals' perceptions of its values and benefits.[181]

Buy-in and knowledge/collaboration for own gain

As stated in Chapter 8 'Buy-in' as a barrier/enabler to collaboration does not explain why an individual is behaving in this way. A lack of buy-in is potentially symptomatic of a wider organisational culture that is not one of sharing/collaborating or attributable to other individual factors in the framework, such as trust, threat/power. Both RDS and locCRN informants reported that not everyone was sharing and engaging in collaborations equally and when it did happen it involved the same core individuals. This was a barrier to collaboration identified from the literature review though only one study posited why this was happening. In the health care sector one study found a lack of buy-in, evidenced by certain team members not attending group meetings, gave a clear message to colleagues that not everyone considered participation worthwhile.[180] In a university setting, with staff involved in curriculum design, observation of group meetings revealed certain attendees not contributing to the discussion.[177] The authors believed the hierarchical roles that existed outside of the collaboration were maintained in the group interactions which had a negative impact on the equal contribution of all members. In the context of this project these points regarding role hierarchies (the RDS national PPI forum is chaired by an RDS director) and the potential ripple effect of certain PPI staff not engaging are interesting and could explain the reports of others' lack of buy-in to share and collaborate.

Seeking knowledge or collaborating for their own gain – specifically to fulfil their role - was identified from the accounts of informants in this project. In the literature 'individual gain' related to sharing rather than seeking knowledge, for example, the qualitative study of railway service employees found some staff shared when they required knowledge from a co-worker immediately or believed they may in the near future.[136] Oncology nurses were motivated to collaborate by individual gain, in this case to obtain the knowledge they desired, rather than altruism which supports the findings of this project.[181] In reality locCRN informants had little choice to seek knowledge as this was the route to deliver on the PPIE objectives. Nevertheless, this may have presented a barrier to others sharing or collaborating and is potentially linked to the concepts of threat/power and trust discussed earlier.

Organisational barriers/enablers

Formalise knowledge-sharing and collaboration

The organisation can play a role and instil a sharing culture by promoting collaboration.[177, 182] Though most informants appreciated they were expected to share and collaborate there was not a great deal of evidence from this project that NIHR national promoted it. The literature revealed upper management's encouragement to share knowledge was a predictor of[134] and positively influenced attitudes and intentions to knowledge-sharing[159] and where this was absent presented a barrier.[161] Similarly, regarding collaboration, encouragement from management had a positive impact.[180]

Although some locCRN informants were in senior roles – and assumed to be in a position to promote knowledge-sharing and collaboration – the main driver was to deliver the high-level objectives. These objectives did not specifically require sharing or joint working across NIHRio. The review of PPI in the NIHR tender documents for new (or renewed) NIHRio revealed a similar picture with no mention of cross-regional or national sharing and collaboration (Chapter 1). This suggests a lack of formalisation of PPI knowledge-sharing and collaboration by NIHR leadership is a potential barrier. In the literature when knowledge-sharing was not part of the workplace culture, employees preferred to concentrate on tasks they believed were part of their role.[134] This reinforces the need to build knowledge-sharing and collaboration into NIHR PPI roles and specifications for NIHRio which may instil more of a sharing and collaborative culture amongst NIHR PPI staff. NIHR could mandate tasks or objectives in and around PPI sharing and collaboration.

9.1.2 Leadership/management

At a regional level, the management structure of informants' own NIHRio was not mentioned as a barrier and most appeared to have a free rein to develop their own local model and workings. However, the data highlighted five barriers/enablers to knowledge-sharing and collaboration attributed to national leadership and management.

Awareness of own knowledge and contribution

From the findings of this project, it was unclear whether all informants, and those they wished to engage with, were fully aware of the knowledge they possessed and what they personally could contribute to a collaboration. Although a few informants thought creatively about what they could share that would be of value to others, most did not venture further than suggesting sharing physical resources such as training.

Regarding collaboration, descriptions of the workings, goals and achievements of the regional and national groups were often vague. None of the studies included in the literature review reported individuals' lack of awareness of their own knowledge and contribution as a barrier to knowledge-sharing and collaboration. This is possibly due to difficulties conceptualising and measuring this as a barrier and the fact that in this project it was elicited through a more thorough exploration of what could be shared/how they could contribute. A specific search of the literature revealed only one reference suggesting tacit knowledge may be in an individual's subconscious which makes sharing even more problematic.[300]

National oversight of PPI

There was a lack of national oversight of PPI that impacted on knowledge-sharing and collaboration. Informants reported uncoordinated regional PPI, for example identifying individuals who were unaware they had a PPI remit, which presented a hurdle to joint working. If there was national oversight of who in each region had an NIHR PPI role, then this was not shared with informants. There is no publicly available central list of NIHR PPI staff. A search of the NIHRio documents and websites to identify PPI staff would be labour intensive and may not produce a definitive list if individuals are not named.

NIHRio and the research funding programmes are managed by different co-ordinating centres (CC) and it was not clear whether this impacted on regional and national knowledge-sharing and collaboration and how connected these centres were. From the background data (Chapter 1) NIHR was described as a distributed entity with each CC holding a separate contract with the DHSC which was said to run counter to collaboration as centres operate towards their contract. One consequence was different PPI reporting requirements of the RDS, NIHRio and locCRN, with the latter having specific performance metrics to achieve. locCRN PPI reports were CRN business rather than PPI business. Annual locCRN reports were prepared and submitted to the CRNCC directly and not compiled into those of the other NIHRio. This meant CRN activities were not widely known to others in a NIHR

PPI role. As neither knowledge-sharing nor collaboration featured in CRN PPI performance metrics they would not be prioritised.

Finally, the RDS and locCRN each had their own mechanisms (newsletters and PPI leads' meetings) for sharing and collaborative working at a national level with their counterparts. It is possible the other NIHRio had their own national groups though only one was identified in the document review, the UKCRF Network.[301] None of these mechanisms appeared to involve any cross NIHRio sharing or collaboration.

Collaboration champions and social networks

As documented in the previous chapter, some regions struggled to progress from knowledge-sharing – if indeed that was happening – to collaboration. Additionally, some of the issues with the national PPI leads' meetings suggest a more sharing and collaborative culture is needed. For example, informants who were new to these meetings struggled to follow what was being discussed. The literature suggests effective and meaningful knowledge-sharing and collaboration requires an understanding of the pre-conditions (antecedents) to these behaviours and of the processes for successful collaboration.[119] Of the empirical studies exploring the barriers/enablers to intra-organisational public sector collaboration one identified a champion as an enabler to joint working.[180] Although in this project there were informants who were keen to progress collaboration they would not be considered champions as they lacked the time - and the skills - to devote to promoting and facilitating regional and national collaboration.

The literature revealed social networks to have a varying impact on knowledge-sharing. For government employees social networks had no impact on knowledge-sharing behaviour.[143] However, in educational settings they impacted positively on knowledge-sharing behaviour[139] and were found to be a determinant of knowledge-sharing.[142] None of the informants in this project mentioned a PPI social network. Considering the issues of the uncoordinated regional PPI landscape, a social network could be a potential enabler to knowledge-sharing and collaboration particularly if NIHR led on the formation of the network as a first step to connect NIHR PPI staff.

Role ambiguity

In the literature role ambiguity was a barrier to collaboration in one study conducted in a health care setting.[181] The specific example was oncology nurses not understanding the role of, for example, advanced practitioners, which led to the latter feeling isolated. This in turn had a negative impact on collaborative working. In the current project one unanticipated finding was that some informants, in both the RDS and locCRN, were unclear of the exact nature of PPI in research delivery. Particularly for locCRN PPI staff, not fully understanding how PPI fits with PPI in other stages of the research spectrum is an issue that is likely to impact particularly upon collaboration. This may have been attributable to the CRN transition as previously, particularly for those who had worked in the topic networks, the focus for PPI staff was very likely to have been research design.

9.1.3 Reciprocating concepts beneath organisational culture and leadership

Organisational culture and leadership represent the functional barriers to knowledge-sharing and collaboration at a regional level and are the key foci for change. However, PPI may additionally be impacted by less concrete and deep-rooted hurdles that can be linked to leadership and the organisational culture. Four concepts have been added to the framework: lack of evidence informed thinking and practice; organisational suppression of PPI; values; legitimacy.

Lack of evidence informed thinking and practice

As demonstrated in the introduction to this thesis, there is a growing PPI literature that covers many aspects of involving patients/public, a substantial proportion was published at the time of collecting the data. Researchers, whose purpose is to produce and draw upon on evidence, are likely to understand and respond more favourably to PPI if they are made aware of the evidence base and frameworks available. However, few of the informants talked about the PPI evidence base or the availability of literature to guide PPI in research, whether they used it to inform practice in direct involvement activities, when supporting researchers with PPI or – in the case of the RDS – when training the methodologists to provide PPI advice.

NIHR national documentation reviewed at the time of conducting this study lacks any reference to the PPI evidence base or conceptual frameworks. The RDS Handbook[286], for example, includes two sentences on why PPI is important followed by one stating it is a condition of funding. In the tender documents only a small number - primarily for NIHRio at the applied end of the research spectrum - stressed the importance NIHR places on the research it supports and there was no reference to the PPI evidence base/literature. The picture was similar for the guidance to researchers applying to NIHR for project funding.

Organisational suppression of PPI

This thesis has drawn attention to a number of disconnects within NIHR that may lead to an unintentional suppression of PPI. The first most prominent one, considering the focus of the project, was the lack of sharing and collaboration. This was attributable to several factors but ultimately detrimental to PPI as staff are not sharing good practice and potentially wasting resources that could contribute to strengthening PPI. Second, that NIHR has multiple separate co-ordinating centres managing different facets of the organisation all with some PPI function which (based on comments from informants) have no remit to work together. The third contributing factor is the decision that methodological advisors, such as statisticians and health economists, provide PPI advice. They may be trained to explain what PPI is and to signpost resources but are unlikely to have had direct experience of facilitating PPI. Fourth, the policy of not sharing detailed feedback on the PPI in funding applications is a waste of public contributors’ time and energy and does little to educate researchers in good PPI. All of the above factors work towards the unintentional suppression of PPI by NIHR.

Values

Beyond the statement that the NIHR puts people at the centre of everything it does, how does the NIHR demonstrate that it values PPI? Although none of the informants expressed doubts about the value of PPI in the research process, the metric driven focus for CRN means the ‘effort’ for PPI is expended on delivering the PPI activities that aligned and contributed to the higher-level objectives at that time. The logical conclusion of this is that value is attached to the PPI activity that contributes to a metric not PPI *per se*. For effective PPI in research studies all stakeholders should agree a statement of values, focused on ‘why we do it, what is important and to whom’ (p1394) at the outset.[302]

Legitimacy

Is PPI a legitimate concept in the eyes of NIHR? The concept of legitimacy has surfaced in the PPI literature when the relationship between researchers and lay contributors has been explored; lay contributors have felt the need to legitimise their involvement in a research project and researchers have questioned the legitimacy of PPI for example by questioning the representativeness of the lay contributors.[303] In the context of NIHR national the lack of explicit values and the disconnects leading to the unintentional suppression of PPI rases questions about the legitimacy NIHR bestows on PPI. So, in addition to a ‘values’ statement NIHR needs a ‘legitimacy’ statement. Explicit PPI value and legitimacy statements from the NIHR could influence PPI staff, public contributors and research communities about the importance of PPI. These statements should be developed between their many stakeholders, PPI staff, public contributors and funded researchers and should provide clarity on why NIHR PPI staff are promoting PPI.

Furthermore, if the NIHR continues to use decentralised/devolved models of PPI without clear form and function (i.e. be ‘hands off’ in its approach to PPI) there is the risk that this is interpreted as a lack of commitment to it and again undermines its legitimacy.

9.2 A streamlined model of NIHR PPI from design to delivery

One of the Going the Extra Mile review recommendations was to ‘ensure that the role of public involvement activities in different parts of the overall system is clear, well-understood and properly co-ordinated’ (p22).[79] The project revealed a range of both physical (materials, activities) and human (public contributors’ knowledge) PPI resources, though little appeared to be shared regionally, or within their own NIHRio nationally. There was duplication in the production of physical resources, the PPI training for NIHR staff, researchers, and the public being a prime example. Regardless of whether individuals wish to share their resources there did not appear to be the mechanisms in place for this to happen beyond the national fora such as PPI Leads meetings. There is a sizeable body of literature focusing on the knowledge-management technological innovations and interventions to assist information- and explicit knowledge-sharing. However, knowledge-management technology is an enabler to help connect people with information rather than a solution to the issue of not sharing.[304] In addition, these technologies must meet the needs and fit the purpose and practices of those who are intended to use them and allow fast and efficient access.[304]

The second resource was public contributors’ tacit knowledge. Tacit knowledge, gained through skills and experience developed over time, can be of high value to an organisation and contribute to its performance.[111] The public contributor informants had a wealth of experience which *they* suggested could be valuable to other parts of the NIHR infrastructure. However, this was not shared and, in some cases, particularly in the funding programmes, was lost when public contributors’ time served on the panel ended. This was compounded by an incidental finding that there was no single mechanism for public contributors to learn about other NIHR PPI opportunities. There were reports of funding programmes and the RDS struggling to identify and recruit lay reviewers and PPI group members. It is surprising that NIHR had not implemented processes to direct experienced public contributors to other parts of the infrastructure.

As well as the benefits to others of sharing public contributors' tacit knowledge, gaining experience of the wider NIHR could improve both understanding of the research pathway and their own practice as funding panel members. In the public sector literature, initiatives such as secondments of staff to other sectors, departments or organisations have been implemented and evaluated to engender knowledge-sharing and learning, primarily in the health care sector. For example, with an increase in the number of patients with diabetes managed in primary care, and a danger of primary/secondary care clinicians becoming isolated educationally and clinically, secondments of specialist registrars to general practice were initiated and evaluated.[305] The authors conclude these secondments provide 'a formal mechanism for mutual education, learning and renewal' (p376). Another study explored whether secondments of clinical and academic nursing staff to Collaborations for Leadership in Applied Health Research and Care (CLAHRC) could increase knowledge translation in NHS partner organisations.[306] The authors reported secondees acquired new skills such as assessing and appraising evidence; for the CLAHRC teams the secondment enabled dual capacity development and ensured complementary skill sets; and for the host and seconding organisations the actions of the secondees increased the breadth of expertise and enhanced care delivery respectively. As there were no studies exploring secondments of public contributors, or anything comparable, it is difficult to draw any conclusions from the above studies. It is unknown whether seconding public contributors to different parts of NIHR has been tried, therefore this would be uncharted territory.

9.3 Future areas of research

This project was exploratory and as such has generated several future areas of research outlined below.

9.3.1 Research directly related to the recommendations

The recommendations described in Section 9.6 and 7, to address the barriers to knowledge-sharing and collaboration and a mechanisms for a streamlined model of PPI highlight a multitude of areas for future research.

Progression of recommendations

Co-creation of recommendations - encouraging a sharing and collaborative culture, mechanisms for a streamlined model of PPI and community of practice - into interventions/projects. Co-create a) an intervention to promote and encourage a sharing and collaborative culture, involving NIHR national and grassroots PPI staff, exploring how best to share tacit knowledge and considering the tools available; b) a community of practice with staff who have a PPI role/remit within and outside of NIHR; c) sharing platform with stakeholders - public contributors, those in a salaried role. Within the co-creation process the potential research designs and relevant outcomes for evaluation of each could be determined and developed into project proposals. This process of co-creation could also be evaluated.

Pilot the studies co-created from the recommendations

Conduct pilot studies of each project to explore implementation, acceptability and impact of each project/intervention and required changes.

Knowledge mobilisation or value creation

Greater sharing and collaboration between different PPI staff and public contributors may generate new knowledge. PPI knowledge mobilisation or value creation between PPI staff from different NIHRio, between public contributors, and between the two groups could be explored.

9.3.2 Changes to NIHR PPI structure

At a macro level it would be interesting to explore the potential for, and outcome of, the co-ordinating centres working together on PPI and take on the role of connecting the different parts of the infrastructure. Also, there was already evidence of joint PPI roles between different NIHRio, how would PPI staff feel about regional NIHR PPI teams who cover all NIHRio in the region, with senior roles to improve the career structure? What would be the impact of opening up the national fora, such as the PPI Leads groups, to other NIHRio rather than their own?

9.3.3 Knowledge management in other NIHR functions

Finally, the recommendations in Section 9.6 could also generate new areas of research into, and have an application for, NIHR knowledge-management of other NIHR staff whose role, as with PPI, has a cross-cutting function such as communications.

9.4 Summary

The focus of this project was on those with an NIHR PPI role or remit, from research design, funding to delivery. Data were collected on PPI provision at these three stages and on experiences of, and opportunities, for regional and national PPI knowledge-sharing and collaboration. Through this data an increased awareness of the issue of duplication of PPI activities and understanding of sharing and regional and national joint working was gained.

There were three key findings from this project. First, from specific informant comments that some people do not even *think* to share or collaborate, reports of the nature of the national fora, and the barriers/enablers identified suggest the culture in NIHR is not one of sharing and collaboration. Changing the culture within an organisation is difficult and as demonstrated in this project, sharing and collaboration can involve individuals from other organisations. Second, the synthesis of data on PPI provision revealed there is duplication of NIHR PPI resources and not a great deal of sharing. Third, NIHR public contributors’ skills and experience could be of benefit to, and they might benefit from an increased awareness of, other parts of NIHR, and there did not appear to be a mechanism for them to learn about future PPI opportunities. Recommendations to address these key issues are provided in Section 9.6.

The positive impact of NIHR on health and social research in the UK cannot be underestimated. From its inception there was a rapid growth in the number of infrastructure organisations funded and formed within a short period. With this rapid growth, and the ethos of placing patients at the centre, it is possible the vision for PPI was not fully developed and resulted in vague guidance to NIHRio on PPI. This may have led to the confused regional landscape reported by the informants in this project, the claims of everyone dabbling in PPI and a variation in practice.

Limitations

The case study design enabled the collection of detailed and in-depth data about PPI from three key NIHR stakeholders in research design, funding and delivery. With this design the choice of cases is paramount though difficult in a complex organisation like NIHR. On the surface the public contributor case does not appear consistent with the RDS and locCRN cases, as they are not salaried NIHR PPI staff. However, they do occupy an important space in the NIHR research pathway, one where PPI is evaluated. In addition, the NIHR research funding programmes hold PPI resources, for example training in PPI and reviewing funding applications, and the tacit knowledge of the public contributors. As this thesis was exploring what could be shared, these resources were of potential value to others within the NIHR infrastructure. The research found that public contributors may benefit from experience of other parts of NIHR, for example, those involved in the design of research studies, and vice versa. This has confirmed the importance of including the public contributor group as a case.

In hindsight, interviewing co-ordinating centre communications teams and PPI staff, particularly those who decide on the direction and nature of the PPI leads meetings, would have been useful. Understanding the relationship between the two co-ordinating centres may have provided some insight into whether this impacted on regional and national knowledge-sharing and collaboration. However, it was not possible to explore the perspectives of every NIHR PPI player and the final selection of cases yielded rich data regarding PPI across the three linked research phases.

The objectives of the project were to document NIHR PPI provision at the three research stages, identify any duplication and opportunities to share, and explore the barriers/enablers to regional and national PPI knowledge-sharing and collaboration. In-depth interviews and document and website reviews were the methods of choice to achieve these objectives. Due to the exploratory nature of the project, the in-depth interviews were wholly appropriate, and the document and website reviews provided supplementary data on resources, sharing and joint working for the RDS and the NIHRio regionally. However, in the interviews only one informant said they had not always engaged in a cross-regional PPI group as it was no longer of value. Methods that afforded participants anonymity, as the quantitative studies identified in the literature review did, may have led to greater disclosure of non-sharing/collaboration behaviours. However, participants in the qualitative studies included in the literature review were open about not always sharing and collaborating. It may be that the informants in this project were, or believed they were, always open to sharing and collaboration.

The issue of reflexivity is covered in Chapter 3 particularly in relation to being an RDS advisor at the time of data collection. This potentially was a limitation if informants felt they could not be honest or their practices were being judged and may have impacted on their responses. However, if this was the case then it does not apply to all informants as some were extremely frank in their responses and had no reservations about criticising organisational aspects of NIHR. Ultimately, I believe any limitations of my RDS role were outweighed by the positives, namely that a certain level of insider knowledge and understanding facilitated the discussions.

As the NIHR is a single organisation the literature review was restricted to intra-organisational or inter-departmental knowledge-sharing and collaboration. There was some evidence from this project that informants did not always consider others in NIHR as part of the same organisation. It is possible that the inter-organisational or inter-agency literature would have been more informative in building a conceptual framework. However, this would have introduced other extraneous factors particularly those specific to the differences in the goals and focus of the organisations/agencies and of the individual employees.

Finally, the data were collected in 2017/18 and it is possible that the situation has changed, and the relevant staff are now sharing and collaborating. However, I am aware locally and nationally that this remains a problem. In my own region, local data continues to be collected to build a picture of the PPI landscape. Although anecdotal, I have recently heard of NIHR national staffs' frustration with individuals refusing to share their PPI initiatives and materials. In the conduct of this project, I also experienced reluctance from some funding programme staff in sharing public contributor guidance documents and was informed they were 'confidential'. This also suggests issues with NIHR's organisational culture.

9.5 Contribution to knowledge

The findings from this project have increased understanding of the practice and delivery of NIHR PPI. This thesis provides a detailed overview and critique of NIHR PPI provision in three key stages of the research process which has not previously been documented. In the RDS most PPI advisors devote much of their time to training the methodologist advisors in basic PPI (and keeping them abreast of PPI resources) and are only involved with the client when bespoke PPI is required. One might question whether this amount of training is necessary and is the best use of resources. Over time, as lessons are learned and documented about PPI in complex studies, there should be less need for bespoke PPI. A perceived gap is to support clients - who according to informants already understand *why* PPI is needed – in *how* to do it and this should be the role of RDS PPI advisors. The public contributor data revealed that research funding applications continue to be submitted with sub-optimal PPI which suggests there is still some way to go to raise the standard of PPI in the development and duration of studies. Regarding the locCRN, this project has identified that some of their initiatives may be better served when conducted at the design stage but more importantly raised the issue of the place of PPI in study delivery. NIHR funded studies constitute a small proportion of those on the CRN portfolio, and many of the rest may not have had PPI at the design stage. There is a need for a consensus on what PPI is achievable in these studies and how locCRN PPI staff can be supported to provide this. The CRN introduced the Early Contact and Engagement initiative in 2018/19[307], presumably for those who are not eligible for, or who have not sought, RDS support, to support researchers, including those who have not yet secured funding, though PPI is not mentioned.

In addition to the comments above, and to echo the findings of the Going the Extra Mile review, NIHR PPI could undoubtedly be improved by regional joint working and the development of networks to share resources and good practices. Greater knowledge and awareness of the roles and remits of their NIHR PPI counterparts and of the resources each possess would facilitate sharing and collaboration. Also, there is often a reliance on the same public contributors in research design and as lay co-applicants of funding applications, and increased collaboration between RDS, locCRNs and other NIHRio could create opportunities to access other and new patient/public groups for their involvement. Training for funding panel public contributors appeared haphazard and could be shared across NIHRio, and a process of validation that they are fulfilling their role would be welcomed, regardless of their level of experience.

The findings advance the general literature regarding intra-organisational knowledge-sharing and collaboration in the public sector. First some new barriers/enablers were identified, namely the need for individuals to have an *appreciation* of the knowledge they possessed and the contribution they could make - and how both could be of value to others - and the desire to reduce duplication as a motivator. Second, some concepts are too broad and meaningless when used in isolation, e.g. silo working, organisational culture. Frameworks of knowledge-sharing and collaboration may be more illuminating if the refined and explanatory barriers/enablers are included under the overarching ones. Third, none of the papers identified explored both knowledge-sharing and collaboration and a finding of the literature review was that the antecedents were similar for both. Where both behaviours are of interest, particularly as knowledge-sharing is ostensibly part of collaboration, these antecedents could be incorporated into one model.

It is difficult to determine whether the new barriers/enablers fully translate to public sector intra-organisational knowledge-sharing and collaboration more generally, specifically due to the organisational structure of NIHR. Few, if any, single UK public sector organisations are of the same scale as the NIHR and as geographically dispersed. Nevertheless, the finding that regional groups had stalled at the sharing information stage and lacked the skills and knowledge to progress to collaborative working is one that would appear to be applicable to any setting or organisation.

Exploring PPI activity has been a useful exemplar for understanding knowledge-sharing and collaboration. PPI as a role is both unique and common place and, in this project, staffed by some at a high-grade and many at a relatively low grade. Unlike some very specialist and technical expertise, explicit and tacit PPI knowledge and resources are of universal benefit within and across organisations that wish to fully involve patients/public in any aspect of their work. In theory PPI knowledge should be easier to share because it is not technical in nature, and what has been learnt in this context could be illuminating to the exploration of knowledge-sharing and collaboration in other settings.

There is a substantial body of literature regarding knowledge management which is defined as an approach to identify, capture, and share the knowledge an organisation possesses.[308] Knowledge in this context encompasses electronic information, documents (including policies and procedures) and the expertise of the employees. The key elements of knowledge management in organisations are people, processes and technology[304] and organisational culture.[309, 310, 311] A literature review of public sector knowledge management reported a concentration of studies in the education sector and calls for research to understand practices in other public sector contexts.[312] The public sector has been slow to adopt knowledge management practices relative to the private sector.[309] This is due to the unique nature of the public sector, the bureaucratic and hierarchical structure, the nature of the work and often high turnover of staff.[304, 313] Specific challenges are a lack of buy in from management, of rewards for employees and an adequate technological infrastructure.[314] It is argued that because of the diversity of public sector organisations there is no single solution to, or 'one-size fits all' framework for, knowledge management.[311] Specifically in relation to this final point, this thesis has provided data on the key elements of knowledge management in a major public sector organisation: the people (the players in NIHR PPI knowledge sharing), the processes (those currently available and how they may be improved), technology (there are platforms that are not well used) and the organisational culture (individual and organisational barriers/enablers). An understanding of these may inform knowledge management of other NIHR functions that cut across the infrastructure, such as communications.

9.6 Recommendations - Overcoming the barriers NIHR PPI knowledge-sharing and collaboration regionally and nationally

There are two key recommendations to overcome the barriers identified regarding changing culture and providing systems for people to connect with each other.

Encouraging a sharing and collaborative culture

Most barriers and enablers relate to organisational culture, both at the individual and organisational (management) level and highlight the need to promote a culture of knowledge-sharing and collaboration. There is a wealth of literature regarding organisational culture and it is widely acknowledged that it is difficult to change.[315] Part of the problem is that culture is difficult to define but also it is 'holistic, soft, … has a historical basis and is socially constructed' (p493).[316] There are two paradigms of organisational culture, anthropological and scientific rationalism.[317] The anthropological stance understands the culture to be 'the dynamic and evolving socially constructed reality that exists in the minds of social group members' (p345).[318] Proponents of this view argue that as the culture has been constructed from the grass root level it is not easy for management to manipulate or change.[319] From a scientific rationalist perspective, culture is just one of the many facets of an organisation that is generated by higher management, which is measurable and can be changed as required.[317, 319] The scientific rationalist perspective suggests a unitary organisational culture but others argue for a pluralist or anarchist perspective.[320] Pluralism suggests the existence of a number of sub-cultures within an organisation, and anarchist that no single culture or sub-cultures exist, merely individuals with their own values and norms. These paradigms and perspectives have implications for the choice of change strategies.

The appropriate strategies to overcome barriers depend upon the culture of the organisation. Based on the findings from this project there is a pluralist or possibly an anarchist culture within NIHR PPI. Taking an anthropological stance this suggests the need to try to understand culture at the grass roots level and work with PPI staff to effect a change.

Even if one accepts that an organisation's culture is not a single discrete component that can be fixed, there are some top-down changes NIHR national could make to support and encourage sharing and collaboration. First, they should compile lists of NIHRio PPI staff and share these with the regions. Second, provide exemplars of what could be shared, and of beneficial collaborative ventures. Linked to this would be incorporating details of locCRN PPI activities in the reports compiled for other parts of the infrastructure, opening up the national PPI leads meetings and newsletters to other NIHRio PPI to improve understanding of the different roles. The respective CCs should also review these national mechanisms to ensure these meet the needs of PPI staff. Third, provide support, training and guidance on effective collaboration. Active sharing and collaboration should be explicit in NIHR PPI job descriptions, in the tender documents and become CRN high level objectives.

Hold a blue skies event focusing on NIHR PPI

NIHR should consider holding a blue skies event, involving a range of key stakeholders – those with a responsibility for PPI (staff and public contributors) from the infrastructure organisations across the regions and respective co-ordinating centres - to re-imagine PPI and how they can meaningfully place patients at the heart of all ventures. Although this has always been NIHR’s ethos, their vision of, and expectations for, PPI are unclear. In addition, if sharing and collaboration are important then the vision should reflect this. There needs to be agreement from each CC on how the NIHRio they coordinate will contribute to the NIHR PPI vision. They can set goals, metrics and deliverables devised with the vision in mind. If this can be made clear and implemented, then the ‘change’ to work in this way will require local leadership to understand pluralistic cultures/sub-cultures that may present barriers/enablers to achieving this. With a clear vision for PPI, sharing and collaboration with others, such as universities, charities and the NHS may be easier to achieve.

An event such as this would enable the four concepts, described earlier and added to the conceptual framework, to be addressed. This would be achieved by calling upon appropriate leaders to provide appropriate evidence and supportive statements about the values the NIHR places on PPI and the legitimacy of PPI in all aspects of the research process.

Within this event they should seek consensus on the role of PPI vis a vis local Clinical Research Networks to tackle role ambiguity, how staff can be supported to advise on PPI in non-NIHR portfolio studies and the place of the Early Contact and

Engagement initiative in this. NIHR should discuss – and perhaps plan to evaluate - whether the current practice of RDS methodologist advisors providing PPI advice leads to clients meaningfully involving patients/public in the development of funding applications. They should revisit the policy of not sharing the detailed PPI reviews from public contributors with funding applicants.

Identifying knowledge and a mechanism to connect those with a responsibility for PPI

This project revealed evidence of a lack of individuals' awareness of the knowledge they possessed and its value to others. Knowledge audits have been suggested as a means to identify the knowledge held by individuals[321, 322] and with new knowledge-management initiatives sometimes a culture audit is conducted to understand the organisational culture.[323] Although some argue that effective sharing of tacit knowledge involves personal contact[304, 324] others propose reviews or 'lessons learned' processes where following a task or activity individuals immediately document what they did and what they learned .[325] This can then be stored electronically and others can search for and access. Consultation with NIHR PPI staff on the most appropriate means to capture and share tacit knowledge (potentially part of a future research project based on these recommendations) or even running small scale trials of which ones work for staff is recommended.

A key issue identified in this project that impacted on knowledge-sharing and collaboration was identifying those in a PPI role regionally, within and outside of the NIHR. Previous research has shown social networks to be an enabler of knowledge-sharing and collaboration[139, 142, 154] but not when they are based on workplace friendships.[126, 143] The terms 'social networks' and 'communities of practice' are often used interchangeably but the former are defined as groups who are connected by friendship, work relationships or a shared interest and communities of practice (CoP) by their shared specialty or role.[326] CoP are specified in the literature as a process of knowledge management.[304, 309, 313, 327] As PPI staff share a role, and potentially the same set of problems, the creation of a CoP may be more appropriate and conducive to knowledge-sharing and collaboration. This would extend beyond NIHR and, within regions, could help to create a sense of community which has been shown to engender workplace trust.[118, 135] In addition, there was evidence that NIHRio PPI staff did not always understand the role and remit of others and a CoP could resolve this problem by sharing ‘practitioner’ profiles. Originating in the private sector, CoPs have been adopted into the public sector, particularly health care, to ‘bring together groups of people working in parallel to share knowledge and to innovate’ (p2).[328] There is guidance on creating public sector communities of practice[329-331] and although there is no single guaranteed approach there are some key common features. These are a) establishing a purpose that is relevant and meaningful to members by understanding the community’s needs; b) having facilitators with the skills and training to create and manage CoPs; c) a programme of activities and on-line interactions; and d) buy-in from senior management.[329, 331, 332]

This is clearly no small undertaking but is something the NIHR have created for other staff groups. In 2018 the NIHR established a directory for Clinical Research Practitioners to ’develop the professional identity of CRPs and establish a means of accredited registration’.[307] Clinical Research Practitioner is an umbrella term for those not registered to a health profession who work with nurses and other health professionals to deliver research. The directory was a foundation for the development of a community of CRPs; the website states members will ‘be connected with fellow CRPs, have access to learning resources and events and take the opportunity to lead your own continuing professional development’.[333]

A similar model could provide the means to create connections between those with a PPI remit and alleviate many of the problems highlighted in this project. If funded in partnership with the NHS, universities, and the voluntary sector this CoP could extend beyond NIHR.

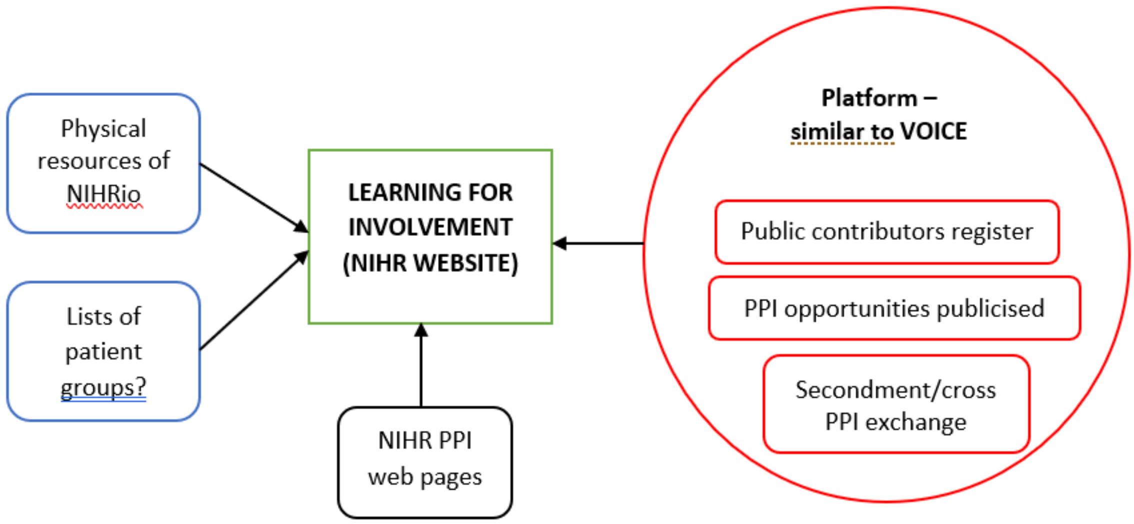
9.7 Recommendations for a streamlined model

From the findings of this project, a streamlined model of PPI is feasible but the mechanisms for this to happen are not fully in place. One part of the knowledge management process is content management, namely making resources available on-line to be shared.[314] The NIHR has a Learning for Involvement website[334] though a search of this website (in June 2021) suggests a paucity of information. Searching for ‘What is PPI?’ generated details of two training resources: a three-module training session, primarily for public contributors but said to be of use to researchers, with a suggestion to allow one to two hours for each; and the details of an upcoming interactive workshop for those working in clinical trials, free only to those within or partnered with University College London’s Institute of Clinical Trials and Methodology. Although these two resources are undoubtedly valuable and well-constructed, they are unlikely to meet the needs of busy clinician researchers wishing to gain a basic understanding of PPI. The NIHR main website has useful information about PPI[335] and it is unclear why this is not consolidated with, or linked to, the Learning for Involvement website.

The website is open to anyone to upload resources and is potentially an ideal platform for NIHR PPI staff – and others - to share resources. This could, with the permission of the individuals concerned, include lists of patient groups. With a greater focus on public health prevention and social care studies NIHR PPI will need to diversify. They will not be able to rely on patient groups traditionally sourced from NHS trusts and NIHRio. The existence of a platform to share resources will enable the inclusion of physical and human PPI resources from, or designed for, local authorities, the care home sector and social care.

As stated in Chapter 8 a register of public contributors – including those in NHS trusts and charities - would provide the opportunities for individuals to be involved in other ventures. Voice, described as a ‘community of members of the public, patients & carers who contribute their unique individual experiences to improve research & innovation’[336] provides a platform for interested members of the public to register and research teams to promote opportunities for involvement and sometimes participation. The adoption of this model and the creation of a platform would enable public contributors to register and provide details of their PPI experience and NIHR PPI staff to publicise PPI opportunities. Incorporating this within the NIHR Learning for Involvement website would consolidate and centralise PPI information and resources (Figure 9.7-1).

Figure 9.7-1 – Recommendation for a streamlined model of PPI



The provision of a platform to promote PPI opportunities corresponds with the final recommendation, that of the 'secondment' or cross PPI exchange of public contributors to different parts of the NIHR infrastructure, both as a learning opportunity and a means to impart their tacit knowledge to others. This could be incorporated into the platform described above along with other opportunities.

As demonstrated earlier, effective knowledge management is a challenge particularly in the public sector. The intended users should be involved in the development or amendment of the mechanism(s) for sharing resources. This will ensure it meets the needs of the stakeholders, and their involvement in the design could lead to greater engagement in its continued use. Co-producing this mechanism and ensuring it is a useful resource for researchers, PPI staff and public contributors could be a key collaborative venture for regional PPI groups and other key stakeholders.

Consolidating information and resources and creating a platform for a cross-PPI exchange and to promote PPI opportunities, could have multiple benefits. It would save time and resources for PPI staff, expand the horizons of public contributors and provide opportunities for learning, benefit those clinical and academic researchers who do not for engage with NIHR to access quality PPI resources.

As discussed in the Methodology and Methods chapter PPI in this project was limited. Going forward, stakeholders' (public contributors and salaried PPI staff) views on the recommendations will be sought. This will be followed by a proposal to work together with stakeholders to develop strategies to progress the recommendations. Applications will be made to NIHR and/or locally from university PPI small grants to fund this work.

9.8 Conclusion

To conclude, the NIHR funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth; in doing this, it puts people at the centre of its work. As a global leader in research, by reflecting on its own processes and practices and by incorporating the findings of this thesis there is an opportunity for the NIHR to become increasingly efficient and effective, communal and collaborative and to improve its offering and experiences for professionals and public alike.

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Appendices

Appendix A- Summarised recommendations from the Going the Extra Mile report

Recommendation 1	**Communication and information** – Improve how the public can learn about and become involved in research
Recommendation 2	**Culture** – NIHR should commission standards for PPI in collaboration with the public and other partners
Recommendation 3	**Culture** – NIHR should include the strategic goals identified in the review, in their overall strategic plan
Recommendation 4	**Continuous improvement –** Provide PPI workforce development initiatives across NIHR
Recommendation 5	**Continuous improvement** – NIHR measure PPI success through the indices of ‘reach’, ‘relevance’ and ‘refinement and improvement’
Recommendation 6	**Co-production** – NIHR should establish a co-production taskforce
Recommendation 7	**Connectivity** – Further support grassroots PPI and ensure it remains the driving force
Recommendation 8	**Co-ordination** – Provide consistent and co-ordinated strategic leadership for PPI, engagement and participation activities through a leadership group
Recommendation 9	**Co-ordination** – Advance and promote PPI, research participation and engagement through clear and transparent strategies and report progress annually
Recommendation 10	**Community –** develop NIHR workstream to tackle diversity and inclusivity in PPI
Recommendation 11	Commission an independent review in three years to assess progress

Appendix B - Growth of NIHR

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
INFRASTRUCTURE	CRN (102)	BRC (11)	BRU (20)			SRMRC	PSTRC (PSSQRC) (2)	DEC (4)	CRN (↓15)	NBC		BRC (BRU) (20)
	CRFs (19)					TRP (2)		MRC-NIHR PC	TRC (TRP) (2)			CRF (19 + 4 new)
	ECMs(14)	HTC (2)	CLAHRC (9)					HTC (8)	CLAHRC (9+4 new)			
		PSSQRC (2)	PRCI									PSTRC (2 +1)
RESEARCH SCHOOLS	SPCR (5)			SPRC (5+3 new)					SPCR (8 +1 new)			
				SSCR (6)				SSCR (↓5)				
							SPHR (8)				SPHR (8+1 new)	
RESEARCH UNITS									HPRU (13)			
										BTRU (4)		
			RDS (10)									

Appendix C – Patient and public involvement specified in the NIHR tender documents for NIHR infrastructure, research schools and units

NIHR infrastructure, research school/unit	Document date	Document	PPI(E) guidance/requirements for applicants
Biomedical Research Unit	2011	Invitation to submit pre-qualifying questionnaire	• Strategy for engaging health care users and the general public. • Strategy for PPI in the work of the proposed Research Unit.
Biomedical Research Centre	2016	Full Application Guidance	• Strategy for PPI, engagement and participation in the work of the proposed BRC; with successful applicant required to submit a fully developed PPI/E strategy by the end of the first year of the contract. • Costs of PPI, engagement and participation (including training and support, fees and expenses for members of the public)
Blood and Transplant Research Unit	2014	Tender guidance	• Details on PPI and engagement in the work proposed by the BTRU. • Costs - These are likely to include out of pocket expenses, payment for time and any relevant training and support costs.
Collaboration for Leadership in Applied Health Research Centre	2013	Invitation to submit application	• Strategy for PPI in the work of the CLAHRC. • Strategy for engaging health care users and the general public in the work of the CLAHRC
Clinical Research Facility	2011	Application guidance	• Strategy for PPI in the work of the CRF. • Strategy in engaging health care users and the general public in the work of the CRF.
Diagnostic Evidence Co-operative	2012	Invitation to submit pre-qualifying questionnaire	The aims of the DECs will be to: • Enable collaboration between clinicians and other healthcare professionals, patients, the IVD industry, staff of at least one accredited provider of NHS pathology services, NHS commissioners, academic researchers including health economists, and patient groups

NIHR infrastructure, research school/unit	**Document date**	**Document**	**PPI(E) guidance/requirements for applicants**
Health Protection Research Units	2012	Application guidance: Stage one	HPRUs will be expected to incorporate Patient and Public Participation, Involvement and Engagement in the development of their proposals and at both governance and individual research activities.
Health Technology Co-operatives	2012	Invitation to submit pre-qualifying questionnaire	The aims of the NIHR HTCs will be to: • work collaboratively with patients and patient groups, charities, industry and academics
Patient Safety Translational Research Centres	2011	Invitation to submit pre-qualifying questionnaire	No Reference to PPI
	2016	Full application guidance	• Strategy for PPI, engagement and participation in the work of the proposed PSTRC; successful applicants required to submit a fully developed PPI/E/P strategy by the end of the first year of the contract. • Costs of PPI, engagement and participation (including training and support, fees and expenses for members of the public). The following activities should be considered: ○ Reviewing documents ○ Attending meetings ○ Attending training courses and conferences ○ Outreach and dissemination

NIHR infrastructure, research school/unit	Document date	Document	PPI(E) guidance/requirements for applicants
Research Design Service	2012	Specification and invitation to submit full application	The RDS will: • Facilitate user involvement in research design. This is likely to require (although is not restricted to) an identified lead for PPI in the senior RDS team as well as special PPI advisor(s), resources for supporting involvement in the design stage, and where appropriate, become actively involved in local PPI networks and groups.
School for Primary Care Research	2014	Invitation to submit application	• Strategic plan for PPI and engagement. In developing your strategic plan you may find it helpful to consider the following: ○ aims and objectives that align with, and support the delivery of, the overall aims and objectives of the primary care department; ○ a programme of activities to deliver the strategic aims and objectives over a given time period. This is likely to include plans for involvement and engagement in individual research projects and research themes, in capacity development as well as in the organisational structure of the department itself; ○ a high-level outline of the resources likely to be required to deliver the strategic plan, including key staff, and their training and support costs; ○ partners and collaborators with whom some aspects of the strategic plan will be jointly delivered; ○ a process for regularly monitoring and reviewing delivery of the plan; ○ a process of capturing examples of impact of involvement and engagement even if this primarily takes the form of subjective accounts rather than research evidence; ○ a reporting line that ensures progress in delivering the plan feeds into the management and governance processes of the department.

NIHR infrastructure, research school/unit	**Document date**	**Document**	**PPI(E) guidance/requirements for applicants**
School for Public Health Research	2011	Invitation to submit application	In its **nature**, the NIHR SPHR will: • Engage with the public and leading public health organisations in England
	2015	Invitation to submit application guidance	The selection criteria will include: • The academic institution's **track-record in public and practitioner involvement and engagement** (including service users and carers as well as public health practitioners); This section should include: • The institution's strategy for public and practitioner involvement and engagement including processes for monitoring and review of its delivery; • Programme(s) of activity that deliver the strategy. This is likely to include involvement and engagement in individual research projects and research themes, in capacity development as well as in the organisational structure of the institution itself; • Resources that the institution commits to involvement and engagement; • Relevant strategic and operational partnerships and collaborations; • Processes for evaluation and capturing examples of impact; • How the institution ensures progress in delivery will feed into management and governance processes.

NIHR infrastructure, research school/unit	Document date	Document	PPI(E) guidance/requirements for applicants
School for Social Care Research	2013	Stage 1 – invitation to submit application	Describe the academic institution's track record and future plans for User, Carer and Practitioner involvement and engagement in research. This section should include a summary of: • The institution's strategic objectives for User, Carer and Practitioner involvement and engagement; • Programme(s) of activity to deliver the strategic objectives including involvement and engagement across the research themes in capacity development as well as the organisational structure of the institution itself. • Resources that the institution commits to delivering the programme of activities; • Relevant strategic and operational partnerships and collaborations; • Processes for monitoring and review that includes capturing examples of impact. • Leadership mechanisms that ensure progress in delivering the plans feed into the management and governance processes of the institution.

Appendix D - INVOLVE publications & Guidelines

Title	Year	Document type	Source
Guidelines on public involvement in research commissioning	2006	Set of seven guidelines for commissioners, researchers and members of the public	INVOLVE Newsletter Autumn 2006
Public Information Pack (PIP)	2007	Four booklets informing the public about research involvement	INVOLVE Newsletter Winter 2006/7
Internal reimbursement and payments	2007	Policy document	INVOLVE Newsletter Spring 2007
Good Practice in active public involvement in research	2007	Leaflet aimed at researchers/research organisations	INVOLVE Newsletter Spring 2007
Do you want a say in health and social care research?	2008	Leaflet for researchers to give to members to the public	INVOLVE Newsletter Spring 2008
Survey of Lay Members of Research Ethics Committees (RECs)	2009	Report of the views and experiences of REC lay members	INVOLVE Newsletter Spring 2009
Patient and public involvement in research and research ethics committee review	2009	Statement to provide clarity and guidance to researchers of NRES requirements for PPI	INVOLVE Newsletter Spring 2009
Payment for involvement	2009	Guidance for payment of the public involved in the work of NIHR	INVOLVE Newsletter Autumn 2009
Senior Investigators and Public Involvement	2009	Examples of different ways and different stages senior investigators have involved the public in research	INVOLVE Newsletter Autumn 2009
Research Design Services and public involvement	2009	Report of RDS plan to promote and support PPI in research	INVOLVE Newsletter Autumn 2009
Exploring Impact: Public in the NHS, public health and social care research	2009	Literature review of PPI	NIHR Report 2010/11
Public involvement in research applications to the National Research Ethics Service	2011	Collection of baseline data on public involvement in applications to the National Research Ethics Service (NRES)	CHECK
Developing training and support for public involvement in research.	2012	Report and guidance for those planning PPI training	In NLs?
Putting people first in research. INVOLVE strategy 2012-15	2012	Strategy	NIHR Report 2011/12
Improving the quality of plain English summaries for NIHR funded research: Review of current practice and consultation with stakeholders	December 2012	Report of consultation	NIHR Report 2012/13
Public involvement in research applications to the National Research Ethics Service: Comparative analysis of 2010 and 2012 data	2014	Review of the information researchers provide on public involvement in funding applications;	NIHR Report 2014/15
Guidance on the use of social media	2015	Report	NIHR Report 2014/15

Website resources

Resource	Purpose	Source
INVOLVE Discussion Forum	Forum for sharing experience and ideas about PPI in research	INVOLVE Newsletter Autumn 2006
People in Research	Searchable database of organisations looking for public involvement	INVOLVE Newsletter Spring 2007
invoNET Library LATER BECAME KNOWN AS THE EVIDENCE LIBRARY).	Repository of reports/articles relating to nature and impact of PPI in research	INVOLVE Newsletter Autumn 2007
INVOLVE Training Database	Searchable information on who is providing training in PPI	INVOLVE Newsletter Autumn 2009
Annotated bibliography (LATER REPLACED WITH EVIDENCE BIBLIOGRAPHY)	References and abstracts on the nature, extent and impact of public involvement in NHS, public health and social care research	NIHR Report 2010/11
Cost calculator and a series of examples of different approaches to involve the public in funding applications and the impact that had.	To support the accurate costing of lay involvement	NIHR Report 2013/14
invoDIRECT	Directory of groups and organisations that support PPI in health and social care research	NIHR Report 2013/14
Evidence Bibliography (see annotated bibliography above)	A summary of references on public involvement in NHS, public health and social care research	NIHR Report 2014/15

Appendix E - Sources for item measurement - organisational factors

Study	Culture	Structure	Leadership	Incentives/rewards	Time
Bock 2002				J, O, R, V, AA, BB, EE, LL, KK	
Bardzki 2004			●		
Willem 2007				●	
Gammelgaard 2007				●	
Gambarotto 2010				PP	
Seba 2012		OO	Z	B	●
Amayah 2013	SS	U	Q	F, Q	
Fullwood 2013		N	II	E	
Kim 2014				■	
Park 2015			A, I,S, MM	A, I, G, U.	
Castaneda 2016	L				
Tahir 2016	Q		W	P	QQ
Vong 2016		U	GG	RR	
Muqadas 2016	N				
Bibi 2017				JJ	
Fullwood 2017		N	II	E	
Li 2017			M		
Masood2017			C	NN	
Tamta 2017				DD	
Tuan 2017			K		
Kim 2018	H, T, X, FF,				
Dey 2018	HH,				
Amber 2019		U, Y, CC			
Rohim 2019	@@			@@	
Hendryadi 2019			TT		
Kipkosgei 2020	D				

●	Developed for the purpose of the study
■	Used established employee questionnaire
@@	How measures developed not specified

Key to authors of measures – organisational factors (Table 2.4-4)

A	Alavi & Leidner (1999)	X	Leana & Pil (2006)
B	Barreto (2003)	Y	Lee & Yang (2011)
C	Bass & Avolio, (1997)	Z	Lu et al (2006)

D	Chae, Seo, and Lee (2010)	AA	Major, et al., (1995)
E	Bock et al.(2005)	BB	Malhotra & Galletta (1999)
F	Chiu et al. (2006)	CC	Moynihan et al (2012)
G	Choi & Lee (2003)	DD	Niehoff & Moorman (1993)
H	Cummings & Teng (2003)	EE	Parkhe (1993)
I	Davenport et al. (1998)	FF	Pastoriza et al (2015)
J	Deluga (1998)	GG	Ragu-Nathan et al. (2004)
K	Ehrhart (2004)	HH	Ranjbarfard et al. (2014)
L	Eisenberger et al (1986)	II	Riege (2005)
M	Fu & Deshpande (2012)	JJ	Ryan & Connell (1989)
N	Gold & Arvind Malhotra (2001)	KK	Seers et al., (1995)
O	Gomez-Mejia, et al., (1990)	LL	Sparrowe & Linden, (1997)
P	Jahani et al (2011)	MM	Syed-Ikhsan & Rowland (2004)
Q	Janz and Prasarnphanich (2003)	NN	Tierney et al (1999)
R	Jauch (1970)	OO	Van den Hooff & Huysman (2009)
S	Jenex & Olfman (2006)	PP	Van Dyne et al (2003)
T	Kianko & Waajakoski (2010)	QQ	Wang 2004
U	Kim and Lee (2006)	RR	Wei et al. (2010)
V	Konig, Jr., (1993)	SS	Levin et al (2002)
W	Kouzes & Posner (2002)	TT	Arnold (2000)

Appendix F – Sources for item measurement – individual factors

Study	Reciprocity	Trust	Power & threat	Organisational commitment	Social networks & relationships	Job satisfaction	Confidence
Bock 2002				FF, K DD, L			
Kolekofski 2003	●		●				
Bardzki 2004			●				
Willem 2007		X	J	HH	●		
Gambarotto 2010							GG
Seba 2012		F					
Amayah 2013	D	D			D		MM
Fullwood 2013				B			
Kim 2014		■					
Park 2015		R, JJ, E			R, JJ, A		
Castaneda 2016							C
Vong 2016				V			
Muqadas 2016					Z		
Bibi 2017		H		P		II	
Fullwood 2017				B			
Masood 2017		M					
Tamta 2017						T; KK,EE	
Tuan 2017				Y			
Kim 2018		U, Q, AA		S			
Amber 2019			JJ, CC				
Garcia-Sanchez 2019		F			G, O, W, LL		
Kipkosgei 2020		BB					
Raza 2020^{A}		NN					
Raza 2020^{B}		NN					

● Developed for the purpose of the study

■ Used established employee questionnaire

Key to authors of measures – individual factors

A	Alavi & Leidner (1999)	U	Leana & Pil (2006)
B	Bock et al (2005)	V	Lyman et al (1974)
C	Castaneda (2010)	W	Maurer et al (2011)
D	Chiu et al (2006)	X	McAllister (1995)
E	Choi & Lee (2003)	Y	Moorman & Blakely (1995)
F	Chow and Chan (2008)	Z	Nybakk et al (2009)
G	Chung and Jackson (2013)	AA	Pastoriza et al (2015)
H	Cook & Wall (1980)	BB	Pinjani & Palvia (2013)
I	DeLone & McLean (1992)	CC	Renzl (2008)
J	Devos et al (2001)	DD	Schaubroeck & Merritt (1997)
K	Gardner & Pierce (1998)	EE	Schaufeli et al (2002)
L	Gecas et al (1989)	FF	Stajkovic & Luthans (1998)
M	Gillespie (2003)	GG	Van Dyne et al (2003)
N	Harold & Darlene (2004)	HH	Wagner & Moch (1986)
O	Hentonnen et al (2014)	II	Weiss et al (1967)
P	Kanungo (1982)	JJ	Willem & Buelens (2007)
Q	Kianko & Waajakoski (2010)	KK	Wong & Law, (2002)
R	Kim & Lee (2006)	LL	Wong (2008)
S	Kim et al (2013)	MM	Za´rraga & Bonache (2003)
T	Law et al (2004)	NN	Eze et al (2013)

Appendix G – Letter from Ethics Committee

Newcastle University

17/07/2014
Jan Lecouturier
Institute of Health & Society
Newcastle University
Baddiley Clark Building
Richardson Road
NE2 4AX

Faculty of Medical Sciences
Newcastle University
The Medical School
Framlington Place
Newcastle upon Tyne
NE2 4HH United Kingdom

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Jan,

Title: Patient and Public involvement in health research: a qualitative study.
Application No: 00774/2014
Start date to end date: 01/05/14 to 30/04/2020

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: **00774/2014**. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During the course of your research project you may find it necessary to revise your protocol. Substantial changes in methodology, or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation.*

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee.*

Best wishes,

Yours sincerely

K. Sutherland.

Kimberley Sutherland
On behalf of Faculty Ethics Committee

cc.
Professor Andy Hall, Chair of FMS Ethics Committee
Ms Lois Neal, Assistant Registrar (Research Strategy)

*Please refer to the latest guidance available on the internal Newcastle web-site.

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www.ncl.ac.uk
The University of Newcastle upon Tyne trading as Newcastle University

The Queen's
Anniversary Prizes
[illegible]
2009

Appendix H – Emails for recruitment

Initial email to Research Design Services

Dear team

I am a researcher and Research Design Service Advisor (RDS NE) based at the Institute of Health and Society, Newcastle University, undertaking a part-time staff PhD.

As part of my PhD I am mapping NIHR patient and public involvement provision for all stages of the research process, from the development of funding applications through to the dissemination of findings. I would like to conduct short telephone interviews with the most appropriate person within each of the 10 Research Design Services. I was unable to find the details for a designated patient and public involvement manager/lead on the RDS XX website and wonder who would be most appropriate person for me to contact.

I am happy to arrange a tele-meeting to discuss this with you further.

With best wishes

Jan

Jan Lecouturier
Senior Research Associate, Research Methodologist and Qualitative Research Advisor (Research Design Service North East)
Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne
NE2 4AX

Telephone: 0191 208 5629

Initial email to chairs of NIHR funding panels

Dear Professor XX

I am a researcher and advisor with the Research Design Service NE based at the Institute of Health and Society, Newcastle University, undertaking a part-time staff PhD.

As part of my PhD I am mapping NIHR patient and public involvement provision for all stages of the research process, from the development of funding applications through to the dissemination of trial findings. I would like to conduct short telephone interviews with the public members of the NIHR funding board about PPI and its place in that setting.

I note from the EME website the public members are (Name) and (Name). As I don't have email addresses for these members I would be grateful if you would forward my request to them, then if they are interested they can contact me directly. I am happy to arrange a tele-meeting to discuss this with you further if you feel it necessary.

With best wishes

Jan

Jan Lecouturier
Deputy Director (Research Design Service North East)
Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne NE2 4AX

Telephone: 0191 208 5629

Initial email to local Clinical Research Networks

Dear

I am a researcher and Research Design Service Advisor (RDS NE) based at the Institute of Health and Society, Newcastle University, undertaking a part-time staff PhD.

As part of my PhD I am mapping NIHR patient and public involvement provision for all stages of the research process, from the development of funding applications through to the dissemination of trial findings. I would like to conduct short telephone interviews with the most appropriate person within each of the 15 local CRN about PPI. I was unable to find the details for a designated patient and public involvement manager/lead on the CRN XX website and wonder who would be most appropriate person for me to contact.

I am happy to arrange a tele-meeting to discuss this with you further.

With best wishes

Jan

Jan Lecouturier
Senior Research Associate, Research Methodologist and Qualitative Research Advisor (Research Design Service North East)
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Appendix I - Topic guides

Topic guide RDS

- Informant background
- Time in post
- Team size, composition

- PPI Provision/model
- Resources
    - Materials
    - Patients/public

- PPI Challenges/more would like to achieve

- Regional sharing and collaboration
    - Within NIHR – out with NIHR

- National sharing and collaboration
    - PIC

- INVOLVE/RDS partnership
    - Understanding
    - Activities

- One NIHR
    - Interpretation

Topic Guide -Funding Panel

- Confidentiality
- Anonymisation

- Background to PPI
    - Experience of PPI
    - Other PPI activities?

- Current panel
    - Which panel?
    - How long served?
    - Training
        - Probe buddy/mentor system
    - Number of public members on panel?
    - How many public members attend each panel meeting?
    - Preparation for panel meetings.
    - Scope of your review (guidelines?)
        - Specific focus
    - What happens at the panel meetings?
        - Views considered?
        - Anything would change about panel meetings/process?
        - Ever anything funded that you disagreed with?

Topic guide CRN Stage 1

- Informant background
- Time in post
- Team size, composition

- PPI Provision/model
- Resources
    - Materials
    - Patients/public

- PPI Challenges/more would like to achieve

- Regional sharing and collaboration
    - Within NIHR – out with NIHR

- National sharing and collaboration

- One NIHR
    - Interpretation

Appendix J - Topic guide locCRN Stage 2

- IF NEW INTERVIEWEEE - Background of interviewee

- Role and team - RECAP ON PREVIOUS/EXPLORE ANY CHANGES IN
    - Role within local CRN
    - PPI team composition

- Transition - RECAP/OR EXPLORE IF DID NOT DO SO IN FIRST INTERVIEW
    - How was it managed, overnight or gradual?
    - Views on move to research delivery focus
    - Impact of transition
    - De-skilling or upskilling?
    - Training required, expansion of team
    - IF NOT EXPLORED/DECLARED IN FIRST INTERVIEW - What happened to people/groups
    - How does PPI 'fit' with delivery focus?

- RECAP ON PREVIOUS PPI/EXPLORE ANY CHANGES IN
    - Local CRN PPI provision?
    - Role in portfolio studies with no/poor PPI
    - Completed, current and future activities
    - Activities evaluated?
    - Experience shared across local CRNs

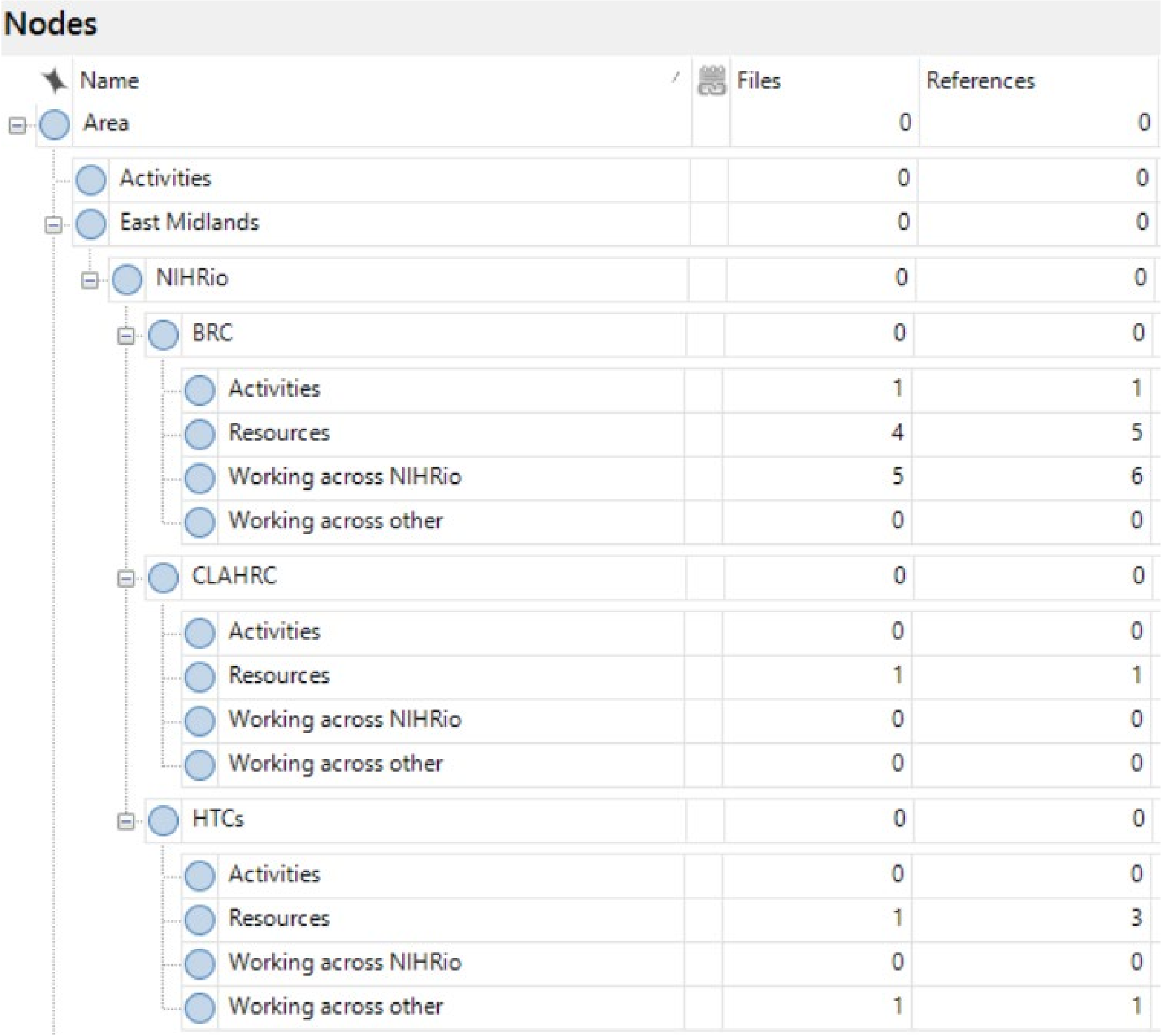
- Progress with National PPIE strategy?
    - Any issues implementing

- One NIHR
    - What does it mean to them
    - How does it relate to PPI
    - Is anything happening in practice

Appendix K – Example of triangulation matrix

Source	Code/categories for regional sharing and collaboration
Document review	No reported connections between the RDS and locCRN One NIHRio reported discussions with RDS on more innovative PPI Reference to CRN collaboration with one other NIHRio
RDS interview	Collaborate with locCRN and CLAHRC through a regional PPI network 'made up of different parts of the NIHR infrastructure' (as part of INVOLVE-RDS contract)
locCRN interview	Collaborate with RDS and CLAHRC – and 'all the different NIHR organisations' - in a regional group.

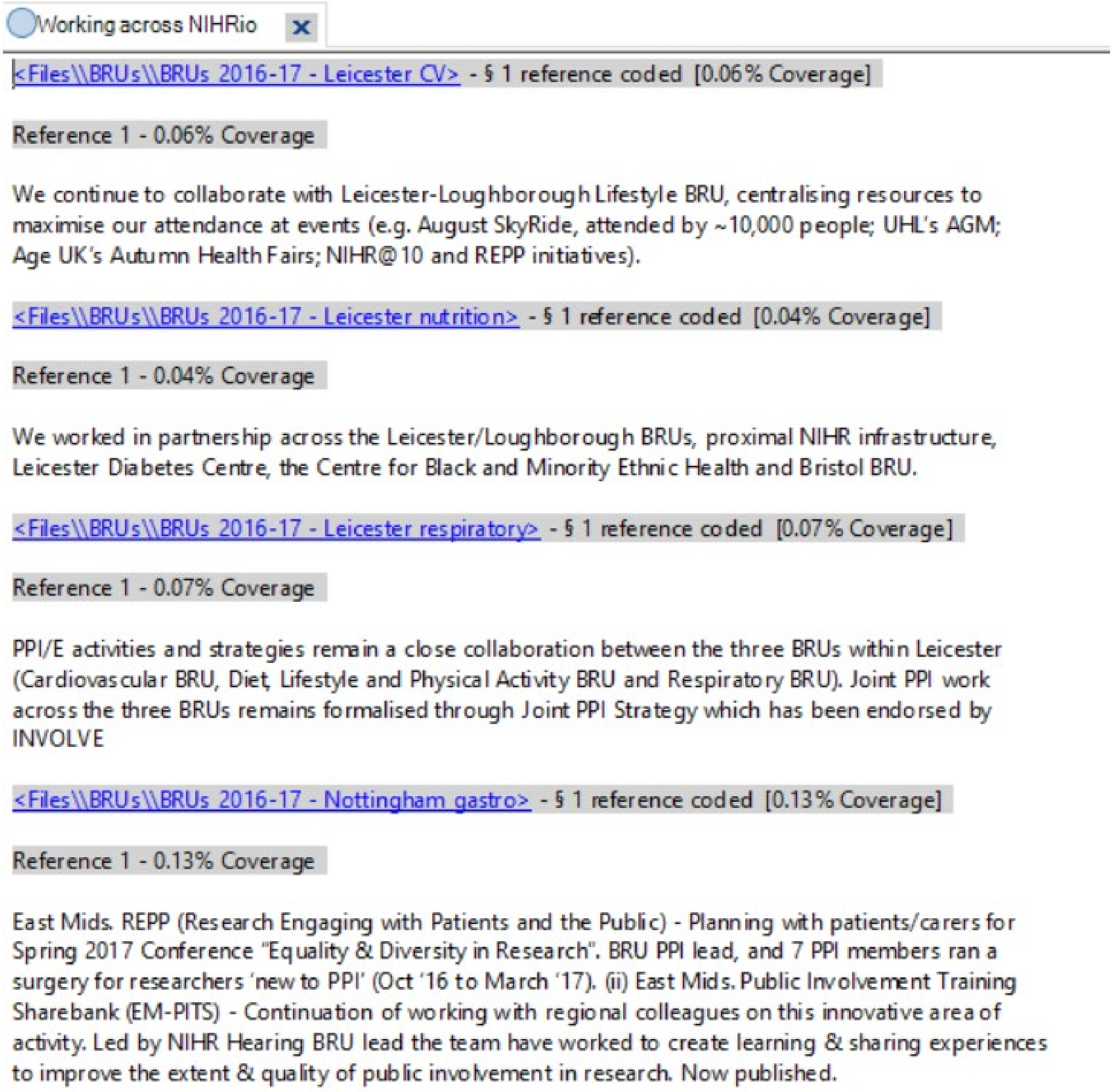
Appendix L – Example of extraction framework for document review



Nodes

Name	Files	References
Area	0	0
Activities	0	0
East Midlands	0	0
NIHRio	0	0
BRC	0	0
Activities	1	1
Resources	4	5
Working across NIHRio	5	6
Working across other	0	0
CLAHRC	0	0
Activities	0	0
Resources	1	1
Working across NIHRio	0	0
Working across other	0	0
HTCs	0	0
Activities	0	0
Resources	1	3
Working across NIHRio	0	0
Working across other	1	1

Appendix M – Example of data extraction nodes – document review



<Files\\BRUs\\BRUs 2016-17 - Leicester CV> - § 1 reference coded [0.06% Coverage]

Reference 1 - 0.06% Coverage

We continue to collaborate with Leicester-Loughborough Lifestyle BRU, centralising resources to maximise our attendance at events (e.g. August SkyRide, attended by ~10,000 people; UHL's AGM; Age UK's Autumn Health Fairs; NIHR@10 and REPP initiatives).

<Files\\BRUs\\BRUs 2016-17 - Leicester nutrition> - § 1 reference coded [0.04% Coverage]

Reference 1 - 0.04% Coverage

We worked in partnership across the Leicester/Loughborough BRUs, proximal NIHR infrastructure, Leicester Diabetes Centre, the Centre for Black and Minority Ethnic Health and Bristol BRU.

<Files\\BRUs\\BRUs 2016-17 - Leicester respiratory> - § 1 reference coded [0.07% Coverage]

Reference 1 - 0.07% Coverage

PPI/E activities and strategies remain a close collaboration between the three BRUs within Leicester (Cardiovascular BRU, Diet, Lifestyle and Physical Activity BRU and Respiratory BRU). Joint PPI work across the three BRUs remains formalised through Joint PPI Strategy which has been endorsed by INVOLVE

<Files\\BRUs\\BRUs 2016-17 - Nottingham gastro> - § 1 reference coded [0.13% Coverage]

Reference 1 - 0.13% Coverage

East Mids. REPP (Research Engaging with Patients and the Public) - Planning with patients/carers for Spring 2017 Conference "Equality & Diversity in Research". BRU PPI lead, and 7 PPI members ran a surgery for researchers 'new to PPI' (Oct '16 to March '17). (ii) East Mids. Public Involvement Training Sharebank (EM-PITS) - Continuation of working with regional colleagues on this innovative area of activity. Led by NIHR Hearing BRU lead the team have worked to create learning & sharing experiences to improve the extent & quality of public involvement in research. Now published.

Appendix N - Annual Strategy Implementation Plan from the PPI&E Strategy

Goal	Objective	Action	Outcome/measures
Talk about research in the NHS	Raise awareness through a variety of media	• Work with patients and carers to produce a range of local and national resources in different media	• Information easy to find and read • Resources tested annually in LCRNs by public survey
		• Develop role of Patient Ambassadors for patients and staff	• Increase the number of patient research ambassadors and evaluate impact
		• Research Familiarisation Workshops organised • Development of a Massive Open Online Course • Delivery of 'Building Research Partnerships' (joint research awareness programme for patients and researchers)	• Public and healthcare workforce are able to access Learning Resources for Patient and Public Involvement
Make it easy for people to participate	Produce a patient experience survey and self-audit measurement tool	• Analysis of patient experience surveys • LCRN self-audit matrix scoring sheet	• Survey patients each year
		• Share practice and findings at a series of regional reviews	• Report on reviews of findings through website, workshops, conferences
		• Identify and solve barriers to participation: coordinated activity across NIHR	• Identified solutions to barriers shared
Reach out – engage communities to ensure greater diversity and wider range of people have opportunity to participate and be involved	Increased awareness of and access to research for patients, carers, wider public, research community and NHS organisations	• Support LCRNs in involvement of patients, carers and the public in NIHR CRN Portfolio Studies	• Reports of specific Projects by Priority Leads working with LCRNs • Numbers of people participating in campaigns and receiving newsletters
		• Identify issues of non-participation and work on issues with particular communities	• Joint working initiative across NIHR setup
		• Reviews of websites, information and communications	• Information of the CRN website in a systematic easy read layout and in a variety of media • Reports from website reviews being carried out by all LCRNS
		• Enhance connections with Funders and Charities	• Positive engagement with those charities that

			fund research on the national portfolio
		- Support national campaigns, e.g. Join Dementia Research, Okay to Ask, UKCTG	- Activity and increased reach reported against each campaign in all LCRNs
Connect with the public, healthcare professionals and partners - we will increase engagement to improve connectivity and will be innovative in the way we communicate e.g. by the use of digital and social media	Work with Information and Knowledge directorate to develop programme of information	Support provided for innovation and sharing of good practice in PPIE across NIHR CRN, the wider NIHR, NHS and external partners	- Google Sites open to public - Twitter followers and data analysis - of trends and key issues
		Training in digital and social media developments and use	Events held and numbers attending training and subsequent use and increase in reach
		Provide information/ support for public partners on using digital platforms	Increase in numbers viewing resources
Support and value patient public involvement and engagement – we will strengthen partnerships making involvement a meaningful and effective part of continuous improvement	Develop a clear national offer for PPIE	Gather relevant information, advice, signposting including guidance for lay people, research and PPIE staff on involvement and engagement	- Implement the new PPIE Strategy - All projects are audited - Quarterly project reports are written - All projects are evaluated
		Work with and support LCRNs to introduce a 'plan, do, study, act' culture to capture the process, learning from involving the public and share practice nationally and internationally	Evaluation process developed and implemented
		To embed PPIE within and across CRN Governance and Directorates	Annual reports demonstrate value, reach, relevance and significance

Appendix O – Full table of resources from RDS, locCRN and public members of funding panels

Activity or resource	RDS	locCRN	Funding panels	Potential for collaboration/sharing
Training RDS in PPI – for advisors	✓			This could be conducted nationally across the 10 RDS
Keeping RDS Advisors abreast of PPI resources	✓			Changes to national resources could be monitored centrally and cascaded to all RDS.
Training in PPI – for researchers	✓			The materials could be shared across NIHRio. NIHRio could collaborate on hosting sessions.
Training in PPI for lay people (including how to review proposals and lay summaries)	✓			The materials could be shared across NIHRio. NIHRio could collaborate on hosting sessions.
RDS PPI Groups	✓			These groups could review funding applications for other NIHRio that are not eligible for RDS. Members of these groups may like the opportunity to sit on funding panels or be external reviewers.
Databases of PPI Groups	✓			These are clearly resource intensive to set up and maintain and could be a shared regional resource across NIHRio
Lay testing of trust websites		✓		
Events to raise awareness/showcase current research		✓		Advertise other NIHRio PPI opportunities
Attend primary care patient group meetings		✓		Advertise other NIHRio PPI opportunities
Advertise studies– posters screens in general practices		✓		
Patient Research Experience Survey (PRES)		✓		RDS – inform research design/processes

Patient Research Ambassador Initiative (PRAI)		✓		Make the PRAs aware of other NIHRio PPI opportunities
Study reviews		✓		
Study walk-throughs		✓		Use these in the development of funding applications – of use to a number of NIHRio
PPI databases		✓		Potentially of benefit to a number of NIHRio
PPI (for the research community)		✓		Of benefit to many NIHRio
PPI resources (for researchers and public)_		✓		Of benefit to many NIHRio
Showcasing the benefits of PPI		✓		Of benefit to many NIHRio
Building Research Partnerships		✓		Of benefit to many NIHRio
Training in reviewing funding applications			✓	Of benefit to many NIHRio
Mentor/buddy programme			✓	