Realising value through patient/public-healthcare professional co-creation for service improvement

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Declaration of Originality: This thesis represents my own work, reflections and conclusions. All other ideas and quotations have been referenced appropriately.

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Abstract

This thesis explores how the public and healthcare professionals work together (co-create) to improve services. It investigates how this co-creation happens in practice and what enables these groups to shift towards more collaborative working. Alongside this, it examines whether there is any point in co-creation. Specifically, does it improve healthcare? This research explores healthcare improvement initiatives mainly across the UK, with some examples from the USA, Sub-Saharan Africa and Eastern Europe. Data was collected retrospectively and prospectively from six organisational case studies and from the experiences of seven individuals. This research was framed by participatory and ethnographic approaches resulting in 55 semi-structured interviews, 160 hours of observations, documents, and secondary data sources.

Existing research has highlighted a gap between advocated public-healthcare professional (PHCP) co-creation and what happens in practice. For some, co-creation is an intrinsic way of improving healthcare, while for others this is a new way of working. Alongside this, there is an ongoing debate about the need to assess the impact of PHCP working.

A marketing theory highlights co-creation as a process where individuals interact with each other and the systems in which they are situated. This study applies this theory and provides the first known exploration of PHCP co-creation as an interactional process in healthcare improvement. This research describes co-creation in practice highlighting how the public and HCPs interact with each other and the wider systems. It explores the factors that facilitate co-creation, and demonstrates what can be achieved when the public and HCP work together.

This thesis shows PHCP working can realise value for individuals, organisations and society, and that the complex, dynamic nature of co-creation impacts how the process can be managed. The research demonstrates conditions that can be engineered to improve how people work together. Co-creation can be facilitated by the individuals involved and through the structures and processes that are used or created. This can shift the public and HCPs towards more effective co-creation for service change.

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I'm indebted to the public and healthcare professionals who let me into their lives. My observations and interviews with you led to many "mini fist-pump" moments where I sensed a real collective commitment to work collaboratively to improve healthcare. I therefore hope this work can be of as much use to you as your experiences and skills were to me. I promise the papers that follow will be shorter, and more accessible.

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I've been privileged to have three fabulous and supportive supervisors. Prof. Derek Bell believed in the vision behind this PhD and supported me through the haze towards a clearer message. Dr. Julie Reed supported discussion, exploration and presentation of this work. Dr. Catherine French provided positive pressure, and practical support that enabled me to complete this thesis.

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We welcomed new lives into this world and said a final farewell to young friends during this PhD. This enabled us to collectively experience the good and the bad in the systems I am keen to improve. I therefore dedicate this work to the memory of Jagraj Singh and Hargobind Singh, and to their respective, amazing warrior wives Sukhmani Kaur and Dalveer Kaur. Your experiences of healthcare an ocean apart highlighted the variations in care that we still have. Our frustrations at various parts of your journeys and the necessity to subvert the system at many points showed how healthcare systems need to be improved to be responsive to need. I continue to work to improve healthcare planning and delivery with your experiences in my heart.

I had already written these acknowledgements when my mother passed away. My parents remained resilient through expulsion, resettlement and everything else that life threw at them. Throughout all this, they continued to fight for the rights of others and ensured we were raised to understand how to best use our privilege to make differences for those who weren't in positions to do so. It is with this mindset they instilled that I have written this thesis - with the aim of making a difference rather than solely advancing my (academic) career. So I add my mother to this list of acknowledgements and thank my father for his continued support.

For Satjoat Kaur and Beyant Singh, the amazing revolutionaries of our present lives and their future world. And their co-creator, Randeep Singh.

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Glossary

Abbreviation	Full term
APPI	Artefacts, Processes, Persons and Interfaces
CCG	Clinical Commissioning Group
CHW	Community Health Workers
DART	Dialogue, Access (to information), Reflexivity and Transparency
EBCD	Experience-Based Co-Design
GP	General Practice or Practitioner
HCP	Healthcare Professional
NHS	National Health Service
NIHR	National Institute of Health Research
PDSA	Plan-Do-Study-Act cycles
PHCP	Public-Healthcare professional
PI	Public Involvement
PPI	Patient and Public Involvement
QI	Quality Improvement
VCC	Value co-creation

1.Introduction

"There's really no such thing as the 'voiceless'. There are only the deliberately silenced, or the preferably unheard."

Arundhati Roy[1]

There is evidence of efforts across the world to engage citizens in healthcare planning and improvement[2–4]. In the United Kingdom, long-standing efforts have attempted to bring patient and public voices into healthcare planning, delivery, and research[5]. For a while, it appeared as though these attempts had a prominent place in healthcare structures. They were underpinned by a tide of legal duties[6–8], recurrent policy and related directives[9–11], and later funding requirements[12]. This was, in part, a response to serious healthcare incidents highlighting what could happen when patient and public voices were silenced or unheard[13–16]. It was also connected with efforts to modernise healthcare services in partnership with patients and the public[17–20]. However, this wave of apparent learning and action has not addressed the gap between promoting these partnerships and getting them into practice[21–24]. This is evidenced by the absence or questionable involvement of patients and the public in recent high-profile, England-wide healthcare initiatives[24,25]. Additionally, practitioners lamented the absence of partnerships with patients and the public from healthcare planning and delivery in the National Health Service (NHS) Long Term Plan (2019)[26–28]. This begs the question, is the policy-level commitment to these partnerships waning, or is this way of working still not fully understood?

At a practice-level, there appears to be continued interest and commitment from specific communities to explore and implement partnerships with patients and the public. Both healthcare research and practice are abuzz with terms such as patient and public involvement, public engagement, and co-production, among others. These terms aim to describe ways of working, and positions people within these processes. The terms position those traditionally seen as being outside of healthcare systems as having vested interests through their roles as patients[29,30], public[31], carers[32,33], consumers[34,35] and citizens[36,37], among others. In an attempt to be mindful of the views of participants in this research, I use the term 'public' in this thesis. The National Institute of Health Research (NIHR) INVOLVE definition for 'public' "include[s] patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services"[38] and is the term I adopt. I use this term to shed light on how public-healthcare professional (henceforth PHCP) partnerships achieve service change. This research aims to add to the evidence base on PHCP working and contribute to the public involvement literature. It does this by exploring this way of working in healthcare planning and delivery and does not explore the healthcare research context.

1.1 Public Involvement in Healthcare

Current evidence shows that involving patients in their own care can lead to efficient and effective decisions, and can be cost-effective[39–41]. Moreover, research shows that public involvement can influence and lead to changes in healthcare planning and delivery[42,43]. This includes the public and communities helping people manage health conditions, and providing information to triage people through existing healthcare systems[39,44,45]. PHCP partnerships have led to responsive improvements to healthcare research, quality and design[46–49]. Commitment to this way of working has created organisations like NIHR INVOLVE that aim to support its practical realisation, and tools to document and assess public involvement[50–53]. More importantly, it would appear there is enough evidence to at least prevent reneging the commitment to public involvement.

Despite this, it is not uncommon for people to question how meaningful this way of working is, relating to both the process of working together, and the outcomes that are achieved. Specifically, meaningful working can relate to the ability of the partners to influence the process or outcome, and achieve transformative change[54,55]. Some have explored factors enabling meaningful involvement including strategies public partners employ to influence the process[56,57]. Others have warned traditional hierarchical power structures and surrounding contexts influence, and limit, the potential of public involvement on health systems[58–60]. Amidst all of this, tokenistic public involvement can still exist that may not add anything notable to health and care[61–64]. Ocloo and Matthews (2016) define tokenistic involvement as that which is asked for, but not enabled to be effective nor taken seriously[23]. Some argue this relates to policies that mandate working with the public in healthcare without the complementary commitment to implement this way of working[21,65]. Tokenistic involvement results in progress that can be slow[41], practice variable[53], and impact questionable[66].

Attempts have been made to understand and strengthen how public involvement and PHCP partnerships achieve impact, and realise ‘value’. This drive connects with wider discussions exploring efficiency, effectiveness, and largely economic value in healthcare[67,68]. Efforts to further understand the value of PHCP partnerships aim to build a case for working with the public at a time where there is increasing competition for finite resources[69,70]. This drive positions public partners as central to efficient and effective healthcare systems through involvement in their own care, or healthcare systems[39,41,71]. Some caution aligning public involvement to what they see as a neoliberal agenda. They argue this can limit public participation and structure it to achieve predetermined organisational plans and goals, including improving quality and realising value[59,72–75]. These agendas can emphasise the individual responsibility of public partners in the push for quality healthcare above the responsibility of healthcare providers and the state[72].

Others seem to use the value agenda to promote and optimise public involvement and its influence on healthcare[39,71,76–79]. Charities that aim to strengthen the public voice in health and social care have stated these discussions need to consider person-centred approaches that are key to realising value[39]. For example, the Realising the Value programme explored alternative approaches for the articulation of value in collaboration with the public and communities [39,80,81]. This programme explored how a "social model of health"[39] can be achieved that realises the value of people and communities as designers and deliverers of more inclusive systems[39,80,81]. Such models and systems would recognise value as determined by people and communities, not just services, and incorporate wider determinants of health[39,80,81]. McKevitt et al.'s (2018) research explored patient, carer, and public involvement in major systems change, and they suggest value could provide an alternative approach to demonstrate the impact of this way of working[77]. Nevertheless, at a practical level, how can the value of meaningful public involvement be explored?

1.2 Value co-creation: A potential solution?

A business approach called "value co-creation" provides a potential way to optimise public involvement in healthcare planning and delivery. Value co-creation describes companies that achieve competitive advantage by co-creating value with customers rather than for them[82–84]. Consider the example of a phone. Companies create analogue mobile phones, and customers use them to call people. Now consider smartphones [Adapted from 85]. Companies still create the actual phone but customers can use the device in a greater number of ways. They can check e-mails, use the internet, and store boarding passes for flights. Additionally, smartphone companies freely share software to enable people across the world, including customers, to design apps. This software enables these people to create apps that can then optimise how they continue to use the phone. Some may use apps to monitor health conditions or track activity levels. This enhances people's ability to personalise how they use the product and ensures the phone work for them.

Value co-creation aims to achieve a competitive advantage by changing the relationship between companies and customers[82]. Ramaswamy and colleagues demonstrate that co-creation shifts the focus from creating value for companies and businesses towards creating value *with* people, specifically customers[82,85,86]. This, then, leads to personalised experiences that have more value for customers, lead to a better relationship between customers and companies, and can create innovations for companies and people[82,85–87]. Ramaswamy and colleagues' contribution to value co-creation focuses on interactional and relational aspects of working to realise value[86,88]. Optimised, high-quality interactions and relationships are the key to realising value from co-creation[82,85,86,88,89]. Co-creation is then an interactional process between humans (customers, employees, and so forth) and non-humans (phones, data, shops, and so forth).

Ramaswamy and colleagues present two ways to create high-quality interactions. Firstly, they provide the Dialogue, Access, Reflexivity[1] and Transparency (DART) model as the "building blocks" of high-quality interactions[82,86]. They demonstrate how the components of the DART model, singularly but also in combination, are fundamental to high-quality interactions[82,85,86]. For example, Dialogue is necessary to enable people to engage and interact with each other and with the surrounding systems. However, when Dialogue is combined with Access to information, the ability of individuals to meaningfully interact is strengthened[82,86]. Secondly, Ramaswamy and colleagues state "purposefully designed platforms" are needed to facilitate engagement and further strengthen the interactions between humans and non-humans[85,86,88]. Greenhalgh et al. (2017) have positioned value co-creation as a potential theoretical framework to improve partnerships in healthcare, including with the public[76]. They focus on the creation of 'engagement platforms' to optimise interactions and relationships[76]. Ramaswamy and colleagues' framework offers a potential solution to challenge slow progress towards consistently meaningful and high-quality public involvement.

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[1] Risk-assessment in Prahalad and Ramaswamy (2004), changed to reflexivity in later work

1.3 A brief note about terms

The brief note on terms provided here aims to give readers clarity. Sub-section 2.2.3 contains a more in-depth exploration of the terms explored and used within this thesis.

This research explores public and HCP (PHCP) co-creation for service improvement as an interactional way of working (1.2). The term co-creation is used in this thesis alongside public involvement, and rather than co-production. In part, this is because I adopt and test Ramaswamy and colleagues' value co-creation framework. The framework poses PHCP co-creation as an interactional process where interactions can occur in a multitude of ways. Public involvement, co-production, and various other PHCP partnerships are manifestations of these interactions. Public involvement is the term with which many of the participants in this research were more familiar, and will be explored further in Chapter 2. This research acknowledges efforts under the umbrella of public involvement that aim to work with the public as partners. However, this thesis takes the position that the continued dominance of the term public involvement can place the public as passive or subordinate actors[72,90,91]. That is, this term can perpetuate a hierarchy between those being involved and those involving[59,64,72,90,91].

Alternative terms such as co-creation and coproduction aim to challenge potential hierarchies and establish a co-llaborative way of working. These terms have been used interchangeably in existing literature, yet there is also an important distinction between these terms[92,93]. Boyle and Harris (2009) stated that "co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and neighbours"[94], and others add it has the potential to equalise relationships between those in power and the public[91]. This thesis argues co-creation may encompass coproduction and less equal or non-reciprocal PHCP relationships, which may occur due to power dynamics in practice[95]. For this reason, the term co-production is applied when used by those who are part of coproduced initiatives, but this research does not group all PHCP co-creation as coproduction.

1.4 Focus of this thesis:

This work aims to explain how to optimise PHCP working in healthcare improvement. It does this through a qualitative investigation of how PHCP working happens in this context and aims to further understand the co-creational process. This study collects data in organisations and initiatives that aim to improve healthcare where the public and healthcare professionals do actually work together. This thesis does, therefore, not explore situations where the public and healthcare professionals do not want to work together. Instead, it explores situations where co-creation between the public and healthcare professionals already happens or where there is a will to embed this way of working.

This research will test value co-creation as a theory to explore whether it can provide solutions to optimise PHCP working. This investigation seeks to understand factors that influence the quality of PHCP interactions and assess what this way of working achieves for healthcare planning, delivery, and improvement. This study explores whether the value co-creation theory more broadly, and the DART model and platforms for engagement more specifically, can help explain the nature and impact of PHCP working.

Ramaswamy and colleagues' contribution to value co-creation has had limited exposure in healthcare. To my knowledge, this research presents the first application of this theory to explore PHCP partnerships for service change. This research strengthens existing value co-creation research by testing its applicability for PHCP partnerships and translates the theory into the healthcare context. Importantly, it explores PHCP co-creation from a practitioner's perspective and presents practicable learning to potentially optimise this way of working for healthcare systems improvement, rather than individual patients' own care.

This thesis aims to contribute to the broader discussions about the effectiveness and impact of PHCP working. The PhD takes the view that the involvement or absence of PHCP partnerships has shaped healthcare planning, delivery, and research. It, therefore, aims to build on existing work that calls for more nuanced ways of assessing the impact of PHCP co-creation that take into account the complex relationship between structures and the interactional nature of PHCP working[95,96].

1.5 Research Questions

This thesis is framed by the overarching research question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

The continuing contextual challenges for healthcare include decreasing finances and increasingly complex demand[97]. Value has been positioned as central to the survival of healthcare systems[67,98], and definitions of this concept include "achieving the best outcomes at the lowest cost"[98] *for* patients. While providing a specific understanding of value, this definition positions patients as passive participants in the process. Other research highlights the importance of working *with* patients[68,80,99], especially to highlight discrepancies between what patients and HCP perceive as value[99]. Patients are seen as co-creators of value particularly through involvement in their own care[39,41,71,100]. However, there is limited research exploring *how* this co-creation of value happens in practice when PHCP work together in healthcare systems, and whether impact can be demonstrated using this term[77].

This research is conducted in a healthcare setting where the economic interpretation of value remains persuasive[68,80,99]. The desire to ensure healthcare realises value for money[101] may prompt some to align public involvement with this agenda. Ansari and Andersson (2011) stress resources, including money, are committed to public involvement thereby necessitating some assessment of its value[70]. This environment may be one of the factors influencing continuing calls and attempts to assess the impact of public involvement [102–104]. Nevertheless, Staley and colleagues, in various papers[96,105–108], emphasise public involvement is a complex process with an inherent difficulty of assessing its impact. Specifically, they challenge existing attempts to assess this impact as being influenced by dominant evidence-based ideologies[96] and state more nuanced ways of assessing impact may be needed. This includes addressing the call to investigate the relationship between the value and the impact of public involvement.

The overarching research question, therefore, aims to widen the debate about the value and impact of public involvement in healthcare. It goes beyond public involvement to look at the broader spectrum of PHCP co-creation. The question purposefully explores co-creation in situations where it is already happening. It, therefore, works with the resources and opportunities available to explore how co-creation can be optimised. Rather than asking what works, it asks *how* can we make co-creation work? Value in this question, therefore, is not solely an economic output. Instead, value is what is achieved through co-creation specifically in the context of healthcare improvement.

This research question addresses this call to understand how value is realised by co-creation through a participatory-framed ethnographic and collaborative inquiry. This approach is particularly suitable as it aims to enable collective reflection on practice and initiate changes, thereby increasing potential and opportunity to optimise PHCP co-creation. This will generate insight into the advantages and disadvantages of the exploration of 'value'.

The overarching research question (1) is comprised of three sub-questions:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*

The value co-creation approach applied in this research states "interactions are the *locus* for the co-creation of value"[82(p19)] and demonstrates the importance of quality interactions to realise value[86,88,89,109]. Question 1 (how can value be realised) and sub-question a. are, therefore, intrinsically linked.

Interactions are crucial to co-creation experiences which is where value is realised[82,89]. The interactions aim to personalise and improve co-creation experiences, which in this case would be for the public and HCPs. These interactions have the potential, according to Ramaswamy and colleagues, to optimise the relationship between the public and HCPs that result in personalised co-creation experiences[82,85,86,88]. Prahalad and Ramaswamy (2004) provide examples of personalised co-creation experiences in healthcare, describing the change in patient-doctor interactions[82]. Patients are now able to use technology to explore and monitor symptoms before visiting the doctor and obtain advice from peers with similar conditions[82]. The patient-doctor relationship, therefore, changes from one where patients follow the doctor's advice to them being active co-creators of their own health[82]. Interactions between humans (patients, peers, doctors) and non-humans (technology, doctor's surgery, hospitals and so forth) influence the experience that emerges. Improving the quality of these interactions is, therefore, crucial to improve experiences, and increase the likelihood that value will be realised.

This sub-question aims to make explicit interactions between the public and HCPs and the wider healthcare systems they aim to improve. It will investigate the quality of these interactions and provide the first test of the DART model to explain PHCP interactions for, and in, healthcare improvement. Additionally, it will introduce the first empirical test of whether platforms for engagement facilitate higher-quality interactions that enable PHCP co-creation in the healthcare improvement context.

This research will provide useful empirical data for Staley and Barron's (2019) assertion that "the quality of the interactions becomes more important than the process"[96], and that this should be a focus when assessing the impact of public involvement. This research will add to the debate about how to assess the impact of public involvement. It will explore what influences the quality of these interactions and their relationship with healthcare improvement. It will, therefore, provide insight that may be useful for the design of future evaluations of public involvement.

These interactions are fundamental to co-creation and crucial to how value is realised. So once more is known about PHCP interactions, the following sub-question can be addressed:

b. *What value is achieved through PHCP co-creation, and why is it deemed value?*

There is continuing interest in explorations of value in healthcare as explored in Chapter 2[71,80]. This, together with the debate about measuring the impact of involvement, necessitates sub-question b. This thesis does not aim to provide an economic assessment of value, but borrows terms that underpin the monetary definition. Value for this research question is, therefore, defined by the research participants themselves and constructed from explorations of perceptions of the costs and benefits of co-creation. It is also demonstrated through observations of PHCP co-creation in practice.

The existing literature states value is unique and determined by what is meaningful to individuals[82,84–86,110]. This sub-question aims to define this uniqueness from examples of PHCP co-creation in the specific contexts of healthcare improvement included in this research. The value co-creation approach used contends that value is realised in, and through, co-creation experiences[82,83,111]. The approach accepts that value is dependent on the situations in focus and defined by the individuals involved[82,84]. Value will be a product of the individuals involved, the context, and how co-creation occurs and evolves[82,84,106]. This sub-question, therefore, aims to use the data collected to add to the evidence base for public involvement, but accepts that the value uncovered may not provide generalisable findings.

The novel and more generalisable aspect of this sub-question aims to understand why value is deemed such. This search aims to provide insight into factors that influence whether PHCP co-creation is *deemed* to have value, rather than focusing on the output or the 'value' alone. It explores whether specific factors can be uncovered that influence how people assess the value PHCP co-creation realises. Such insight could be useful for future PHCP co-creation and provide useful data for the debate about how to assess the impact of this way of working.

Finally, the context of this research provides apt opportunity to explore:

c. *How and why does the use of QI methods facilitate or impede PHCP co-creation?*

Chapter 2 describes how quality improvement (QI) methods from industry have been adopted in healthcare improvement initiatives. These aim to provide a method for healthcare improvement and can facilitate PHCP working[112–114]. Smith (2016) found that QI methods were participatory and provided "a structured approach" that facilitated PHCP working[113]. The methods enabled PHCP to learn together over time[113]. Renedo et al. (2014) found QI methods facilitated public involvement through "data collection and reflection" on practice, but that these methods could disengage public partners from aspects of the improvement initiatives[114]. However, the evidence about the influence of QI methods on PHCP co-creation remains sparse. It often comes from one QI programme or organisation, or focuses on one QI method. It seems opportune to use the multiple research contexts in this study to explore the relationship between different QI methods and PHCP co-creation.

This sub-question aims to provide empirical data from a range of contexts where QI methods are used. This thesis explores the use of QI methods in these various contexts and provides learning about how they influence PHCP co-creation. Crucially, this sub-question will use value co-creation as a theoretical framework to understand why and how this happens. This sub-question seeks to provide an explicit analysis of DART and co-creation using of QI methods. It explores how QI methods facilitate or impede DART between the public and HCPs. additionally, it will assess how these methods influence interactions between the public and HCPs, and the healthcare systems they aim to improve.

This part of the research, therefore, aims to optimise the use of QI methods in situations where they may already be used.

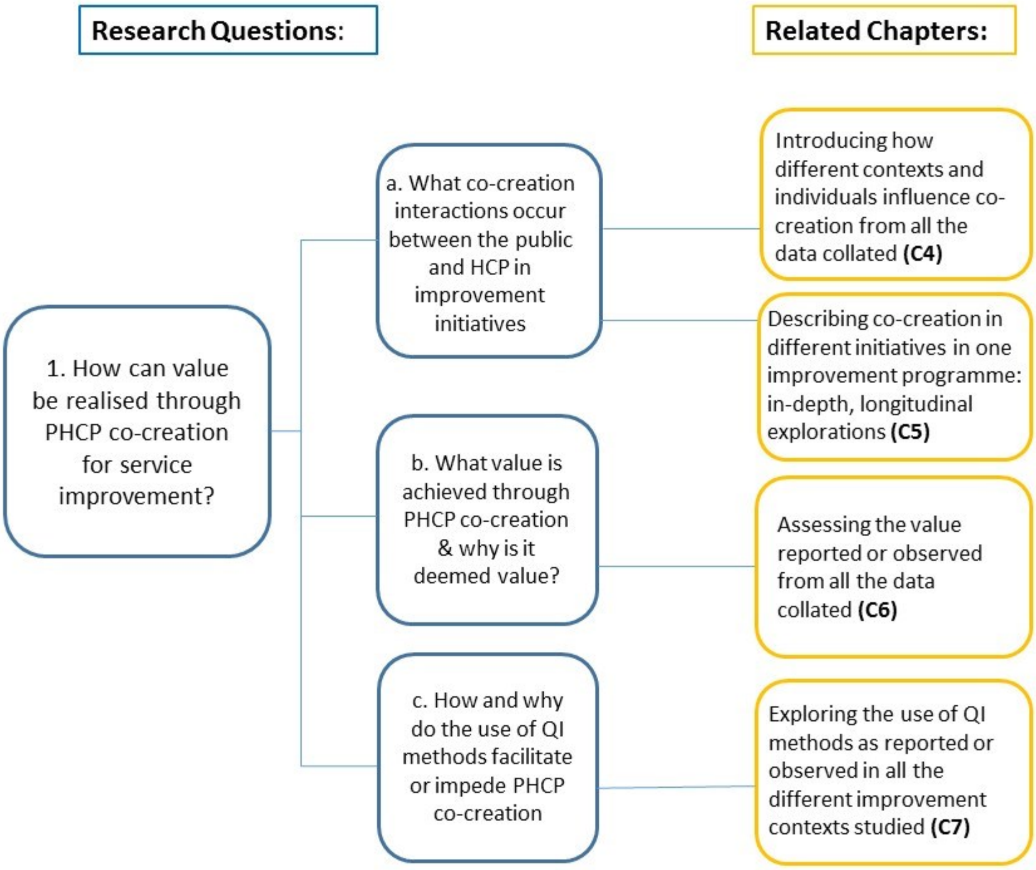
1.6 Thesis structure

This thesis is composed of eight chapters. This chapter introduces the research, study context, and the overall thesis structure. **Chapter 2** brings together healthcare improvement, public involvement, and value co-creation literature. It describes what could be seen as three independent fields and presents them as potentially synergistic bedfellows.

Chapter 3 then frames the research and introduces the methodology, design, and methods. It presents an approach that aimed to be pragmatic and participatory, in order to bridge the gap between research and practice. It describes a journey to produce research with methodological rigour that is useful for practitioners.

Chapters 4 to 7 present findings from the empirical data that were collected from a range of improvement initiatives where the public and HCPs worked together for service change. The research largely explores improvement organisations and initiatives from the United Kingdom (UK) NHS. One example came from the United States of America, one from Eastern Europe, and some from Sub-Saharan Africa. Figure 1 presents the chapter outline describing the order of the chapters, and maps how they relate to the research questions that framed this research.

Figure 1: Chapter Outline



Further details about the contents in the results chapters (4-7) is given in the following paragraphs.

Chapter 4 combines all the data and presents findings showing PHCP co-creation is influenced by the interplay between individuals and the surrounding context. This chapter briefly introduces the contexts of this research and explores how surrounding systems can be created to facilitate PHCP co-creation in healthcare improvement. The study then demonstrates how individuals engaged in PHCP co-creation and the specific roles they adopted.

Chapter 5 presents the findings from four improvement initiatives. It describes a longitudinal journey that demonstrates the complex nature of PHCP co-creation in, and for, systems change. It builds on the application of value co-creation theory in Chapter 4 that highlights co-creation is a dynamic process.

Chapter 6 answers the question co-creation practitioners may at some point face. What is the point of the public and HCPs working together to improve healthcare systems? Does this way of working add anything more than could be achieved without PHCP co-creation? This chapter provides some answers to these frequently asked questions from the wide range of examples gathered from different healthcare improvement contexts.

Chapter 7 uses the unique context surrounding this research to explore the use of QI methods. It makes explicit the relationship between PHCP co-creation and the use of these methods in contexts where they are already used.

Finally, **Chapter 8** brings together the key findings from this research and provides the conditions, behaviours and principles, and supportive practices that optimise PHCP co-creation. The chapter then outlines the main empirical and theoretical contributions to the healthcare improvement, public involvement, and value co-creation literature and practice. This chapter reflects on the academic, economic, and social impact of this research, the study design, including limitations, and provides recommendations for further research and for policy-makers and practitioners.

2. Healthcare improvement, Public involvement and Value co-creation: A review of the literature

This chapter presents literature relevant to investigate how the public and healthcare professionals (HCPs) work together in healthcare quality improvement. As the previous chapter demonstrates, this brings together public involvement and healthcare improvement. The introduction to the literature in the last chapter introduced value co-creation as a potential theoretical framework. This chapter provides an exploration of these three different fields to understand the gaps and issues that still need to be addressed.

Existing research from healthcare (quality) improvement provides useful insight into the context in which this research will be conducted. This context is different to healthcare research where considerable public involvement has been conducted. It is, therefore, important to become familiar with healthcare improvement and understand the existing research on public-healthcare professional (PHCP) working in this context. This in-depth exploration is needed to understand the historical context and the nature of public involvement through the literature. This will make explicit the broad direction public involvement is taking, and the issues that are arising. Since value co-creation has been positioned as a potential theory to improve how people work together, a review of the relevant literature will provide an understanding of this theory, and provide the basis for the research questions of this thesis.

This chapter is structured as follows. It briefly introduces healthcare improvement and quality improvement. It then moves on to a more in-depth exploration of the public involvement literature. Following this, an introduction to value co-creation is provided. I conclude by making explicit the gaps presented in the literature, and finally, I present the research questions that this thesis aims to address.

2.1 Exploring the context: Improving healthcare

There have been extended aspirations and attempts to achieve high-quality healthcare. Reports and inquiries in the USA and UK highlighted systemic conditions in design and delivery that enabled errors in healthcare[13,14,115]. These can lead to unwarranted variation in the quality of care, or healthcare outcomes,[112] longer access times[20], and safety issues[116]. In the UK National Health Service (NHS), a series of systemic failures provided fuel for improvement efforts[13,14,117]. Healthcare improvement occurred before the use of industrial-influenced Quality Improvement (QI) methods among the earliest doctors with their limited knowledge trying to improve their patients' health[118]. This first wave of ad hoc improvement efforts took place without wider supporting structures or established processes[118]. It was followed in the West by a second wave in which new scientific discoveries, and knowledge about treatments and safer conditions, led to improvements to healthcare standards[118]. Waring et al. (2016) state the third wave of safety initiatives began in the 1950s and embedded a structured QI framework to quality and safety, and a fourth wave in the 1990s brought these efforts into policy[118].

This structured QI framework for quality and safety brought different approaches and methods that were adopted and used in and for healthcare improvement[112,119,120]. This, in part, stemmed from a view that healthcare improvement necessitated methods[112,121]. Boaden et al. (2008) state "the main issue is the way in which the improvement is implemented, rather than the nature of the improvement itself"[122(p17)]. Sometimes improvements are successful, and sometimes they are not, and it is not always clear why[123]. Supportive surrounding systems can enable healthcare professionals (HCP) to improve healthcare, but surrounding systems do not always facilitate this[124,125]. Improvement may sit alongside competing agendas and it is not always clear what each activity aims to achieve, how it should be achieved, and what should be prioritised [122,125–127].

Healthcare improvement is therefore more complex and this has led to efforts to define quality and search for methods that can support improvement, as discussed in the next sub-section.

2.1.1 Quality and improvement in healthcare: definitions

There are variations between how quality is defined through policies and strategic documents and how it is understood in practice[128]. Quality is conceptualised differently by country, in various parts of healthcare systems, and by individual healthcare professional groups[128]. Research describes how quality is defined, and by whom, influences efforts taken to achieve it[125,129]. Defining quality of, and in, healthcare is an important and complex part of assessing and measuring it[130]. The Institute of Medicine, when defining quality of healthcare in America, proposed six domains: safe, effective, patient-centred, timely, efficient, equitable,[131] which have continued to influence how quality is understood globally[132]. In the UK, healthcare policy positioned quality from patients' perspective, prioritising three key dimensions: safety, patient experience, and effectiveness[20,116]. Doyle et al. (2013) stated patient experience was crucial and could not be "divorced from the 'real' clinical work of measuring and delivering patient safety and clinical effectiveness". Further research supported positioning "patient involvement and experiences as a source in QI"[128]. However, the drive to improve quality in healthcare *and* ensure that the public are involved in shaping quality appear to be separated as parallel efforts.

Following on from the varying definitions of quality, there are also different definitions which lead to the adoption of specific approaches. For example, Boaden et al. (2008) position QI as a "complex intervention that typically involves interrelated parts"[122]. These interrelated parts include QI methods, as discussed in the next sub-section. A full review of QI definitions is outside of the scope of this research; therefore, this study settles on Batalden and Davidoff's (2007) definition of QI in healthcare:

> "… the combined and unceasing efforts of everyone—healthcare professionals, patients and their families, researchers, payers, planners and educators—to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development."[133]

This definition sets up a collaborative approach to achieve improvements in healthcare including through public involvement. This could embrace PHCP partnerships as a process to achieve change.

2.1.2 Quality Improvement methods: from industry to healthcare

Literature states a method is needed to improve quality in healthcare[112,121,122]. Specific methods to improve quality have been created and successfully used in industry. These aimed to improve efficiency and effectiveness of businesses to optimise profits. Some of these will be briefly discussed before expanding on their use in healthcare.

The "quality trilogy" positioned quality improvement (QI) alongside quality planning, and quality control as processes necessary for quality management[134]. Juran (1986) defines QI as "the process for breaking through to unprecedented levels of performance"[134(p21)]. QI has roots in industry and it has a multitude of approaches which evolved into related approaches, methods, or tools to facilitate improvement in practice[122,135]. These approaches aim to improve quality of goods, therefore reducing costs and achieving competitive advantage over other businesses[136–138]. Some of the main QI approaches used today, for example, Total Quality Management (TQM), Six Sigma as well as their evolutions and variations, were established during post-war industrialisation[112,118]. Although focusing on improving processes, they positioned humans as central to improvement.

Workers who were part of the production process were empowered as part of QI approaches to take responsibility for quality improvement. Toyota established the Andon cord to enable any worker to stop the production line if they saw quality issues[139]. Deming (1986) also positioned customers as central and influential to production[136]. He stated customer satisfaction was key to their continued engagement with the producer and their products, and that producers should use customer feedback to modify and re-design goods[136]. Yet there was a hierarchy between producers and customers: producers were seen as the ones in charge of goods and service creation[136,137]. From the 1950s, QI methods were promoted and used within healthcare settings, finding considerable uptake from the 1990s (sub-section 2.1.3)[112,118]. But could QI help improve healthcare, or would it simply reinforce existing power structures between various healthcare professional groups and the public?

2.1.3 Use of methods in healthcare

There have been attempts to investigate how to reduce variations, and improve safety and experiences in healthcare[20,115,131]. As part of this, there have been broader discussions to establish more scientific ways for improvement[121,140]. These focus on advancing the effectiveness of improvement efforts by strengthening theoretical underpinnings, academic investigation, and even positioning the use of QI methods as a "superior" way of learning about improvement[121,140].

Efforts have been made to adopt, adapt, and assess the use of QI methods for healthcare improvement[141–145]. This has highlighted the potential of using QI methods for improvement:

> "We have heard stories about how people had not worked across boundaries before and how valuable it was to see the bigger picture. Simply sitting down together to create a flow chart and understanding who does what in a complex process was then, and remains now, an eye-opener."[112]

However, evidence shows the extent to which these methods influence improvements in healthcare and patient care is limited[120,124,144–146]. Existing research points to use of these methods with fidelity as a potential solution to increase their effectiveness to improve healthcare[143,145,147,148]. Walshe (2009) warns rather than improving healthcare, the quest for such methods has inadvertently perpetuated an industry of 'pseudoinnovations'[120]. That is, the search, reinvention, and adoption of endlessly new methods becomes counterproductive and takes over from the focus to improve healthcare[120].

One of the key methods adopted from industry and relevant to the focus of this study, is the idea of people working together to improve healthcare. To this end, differing models of 'collaboratives' have been used as a method to drive and learn from improvements in practice[122,149–151]. These often have diverse foundations often from the industry methods previously introduced, for example, the Breakthrough Collaboratives[150] have come from TQM[152] (2.1.2). Such collaboratives aim to challenge silo-working and bring together diverse groups of people to capitalise on their knowledge, skills, and networks [122,151,153–155]. Collaborative healthcare improvement has involved patients, including as experts alongside HCPs; actively making improvements; and highlighting areas where changes and improvements should be made[112,149].

2.2 Role of Public Involvement in Improvement Efforts

This sub-section describes a brief history of public involvement (PI) in the NHS and in so doing, it uses various terms to describe the people (for example, public, patient and so forth) based on how these individuals were defined by the related literature.

2.2.1 A brief history of public involvement in the NHS

There is a long-standing history of PI in health services in the United Kingdom. A context of "renewed interest in public and citizen participation"[156] provided the backdrop to wider community-led involvement, exemplified by the disability rights[156] or the trade union[157] movements. The 1990s saw a pervasion of a government-led drive to involve the public in shaping and modernising the NHS. The government introduced a programme which would improve quality in the NHS, tackling variability while reforming the system to deliver personalised, patient-centred care[17]. This programme stated that PI, and partnering with communities, would be promoted more generally, and patient and carer involvement would be a core feature[17]. In subsequent years, various policy[9,19] and legal drivers[6,8,158] led to the creation of organisational structures[159,160] aimed at facilitating PI.

PI became a central part of NHS improvement and modernisation efforts in the mid-1990s. In the drive to establish services around the needs of patients, policies established partnerships between them and the NHS[9,17]. Both patients and the public were positioned as strategic actors within the organisational NHS structures that planned healthcare[9,17]. Patients were seen as key to influencing their own care, and public-healthcare professional working was positioned to responsively shape improvements in healthcare systems[9,18,19,161]. This policy reform that aimed to strengthen PI, occurred alongside the realisation that serious failures of patient care in the NHS had occurred. These failures strengthened the resolve in policy-makers and HCPs to reposition the public as partners[13,14].

Systematic failures at Royal Liverpool Children's Hospital[14] and Bristol Royal Infirmary[13] uncovered exclusive environments with a disregard for the needs of patients and parents. At the former there was widespread retention posthumously of children's organs without parental knowledge or consent[14]. At the latter, there was poor quality and safety issues with cardiac surgery resulting in high levels of mortality[13]. Both inquiries emphasised a lack of compassion and disengagement of patients from the care process[13,14]. The Kennedy report on the Bristol failures recommended that resources were committed to ensure PI was embedded into the structures of the NHS and focused on improving its quality[13]. This report advised patients and the public be given access to data about the quality of the organisations, and to be able to shape such information through their own perspectives to establish a patient-centred culture[13]. Significantly, it recommended evaluating mechanisms used to involve the public to assess what works[13].

The calls and efforts to strengthen and improve PI in the NHS were multipronged. Legal duties established regulatory requirement for NHS trusts, Primary Care Trusts, and Health Authorities to involve patients and the public[8,159,162,163]. Previous structures for participation such as community health councils had lacked power[13] and not been valued by people working in the health service[5]. Subsequent structures such as Patient and Public Involvement Forums (established in 2003), Local Involvement Networks[164] and then Healthwatch[165] each aimed to embed involvement in ways the previous structures had failed. Alongside this, the Patient Advice and Liaison Services were established[19] to mediate between healthcare services and patients and the public, and act as an avenue for information provision and complaints[19,166]. Yet there were concerns about the implementation of these efforts to enable the public to shape healthcare planning, delivery, and research[167]. Specifically, that the ability to establish effective, influential infrastructure for PI was not fully understood or explored[167].

The first national survey collecting patient experience data was another mechanisms to ensure services were hearing from people who were using them[17,18]. The survey aimed to evidence whether services were meeting the needs of patients, even if they were not involved as active partners within NHS structures. Collation of such data aimed to provide national comparisons[17], and sat patient experience equally alongside other indicators that influenced the funding NHS organisations would receive[19]. National patient experience surveys provided patients with a voice and positioned such data and its collection as instruments for judgement. As an unintended consequence, the surveys and their subsequent variations became tokenistic and created a "compliance mentality on behalf of management boards"[168(p67)]. Along with formal or informal complaints made by patients, this feedback has not been positioned or viewed as mechanisms for improvement[58,169,170].

2.2.2 The role of the public in improvement efforts

Public involvement and patient experience have been highlighted as key factors in policies focusing on modernising and improving quality in the NHS[18,20]. In some contexts, industry-established QI methods and approaches which centre on the customer have been used to support the practical realisation of this aim[136,171,172]. These methods aim to provide systematic approaches to continuously improve the quality and value of products and services based on the needs and desires of customers[171].

Bottom up approaches for improvement, for example, through social movements have been proposed as having potential to motivate and mobilise people in achieving effective and timely improvements in the NHS[173174]. People in these movements "convert" their peers and so form the critical mass of support for sustained change and improvement"[174(p64)]. The public have "acted as *technology of persuasion"* influencing discussions[78(pe42)] and encouraging the collection of data to assess or inform improvement, spread interventions[114], and influence the focus of improvements made[57,175]. Additionally, PI has influenced changes to existing healthcare services or established new ones[42,43,104]. Establishing PHCP partnerships as a way of working has led to co-designed improvements based on experiences of using or delivering services[49,176]. Such partnerships have created and used innovations that provide alternatives to existing treatments[177] or aim to facilitate or enhance the patient journey[178,179].

Multidisciplinary teams have encouraged collaboration between different groups of healthcare professionals, with some of these featuring patients as team members, working alongside professionals to realise improvements[112,149,180]. Public participants in QI projects have stated such a way of working has been crucial to facilitating implementation of the improvements as well as increasing their abilities to influence[181]. Additionally, the public participants played roles in facilitating collaboration between different professional groups, including across various organisations[181]. Renedo et al. (2014) conclude that while specific elements of QI culture can facilitate public involvement, further research should be carried out to test this across different QI organisations[114].

Methods and guidance have been created to provide information and structure on how the public and HCP can work together in healthcare improvement. Methods such as Experience-based Co-design, mapping patient journeys, and simulation are used to bring people and their experiences together to conceptualise problems in healthcare and shape potential solutions[176,182–184]. Alongside these methods, there have been concerted efforts to create guidance, frameworks, and review evidence to support people (often HCPs) in working with the public in healthcare improvement[48,185–188]. These efforts aim to provide the underpinning rationale for adopting this way of working and make explicit factors that influence it[48,189,190]. O'Hara and Lawton (2016) state "healthcare organisations should value, support and provide resources for the act of seeking to engage with patients and their families in the design, measurement and improvement of services"[58]. PI in "improvement work can be beneficial and play an important role in achieving the desired changes, but requires careful management if its full potential is to be realized"[78]. While there is evidence that organisations are providing some support through the creation of such guidance, some may question whether this is enough since the public are not always involved in healthcare improvement.

PI in QI has not become systemic, systematic, or 'normal' in practice, and may not yet be achieving its full, transformative potential[25,55,63,64,78,191–194]. That is, the knowledge, skills, and abilities of the partners are not always seen as legitimate and able to influence the partnership, and what it aims to achieve[55,195]. There can be tensions in what HCPs and service users believe are legitimate ways for their involvement to shape healthcare improvement[193,196–198]. HCPs may disregard public voices, or restrict involvement to specific areas, for example, helping with the creation of easy-to-understand communication or patient information[25,154,197]. This can reinforce rather than challenge existing power hierarchies and limit or structure the influence the public have in improvement initiatives [23,59,199]. For example, it has been stated that in practice organisations can put their aims and assumptions above the needs and preferences of patients[200]. This can influence how the public and HCPs work together and how that is defined, as discussed in the next sub-section.

2.2.3 Involvement, coproduction or co-creation?

Power dynamics between the public and healthcare professionals influence how they work together[23,59,193,196–199]. These power dynamics can hinder participation or limit the influence the public have on healthcare planning, delivery, and improvement[23,95,192,201]. One of the ways this happens is through the creation and use of spaces where the public are invited to participate[37,59,75,199]. While these spaces can be crucial in enabling people to participate and influence, they can also structure and limit the influence of the public and focus on the institution's agendas[37,59,75,202–204]. The wider neoliberal influence in healthcare may further structure and define the role of the public and what aspects of healthcare they can influence[60,64,73,93,181,205]. PI has been said to be a "transitional and developmental process"[114] in healthcare, with its aim, scope, and potential influenced by its context, including organisational cultures[114]. Evidence suggests that policies to drive the national public involvement agenda remain unclear both about what they aim to achieve and how[21]. All these factors can influence the realisation of meaningful involvement (defined as "involvement with influence"[206]) compared to tokenistic involvement[59,186,203]. Ocloo and Matthews (2016) define tokenistic involvement as that which is asked for, yet not enabled to be effective or taken seriously[23]. They argue current narrow, exclusive modes of involvement perpetuate this tokenistic working[23].

One solution to challenge tokenism has been to create methods that aim to facilitate meaningful involvement and its reporting. Frameworks and standards have been created that support individuals in planning PI[206,207]. These aim to provide people with the structure of what good involvement looks like, or guide them to plan and make explicit how they will realise meaningful collaboration[206,207]. Additionally, guidelines have been created to support better, more meaningful reporting of public involvement[208,209]. These aim to standardise and improve the quality of such reporting to share learning and build an evidence base of impact[189,208,209]. It appears these guidelines attempt to improve practice through a cycle of better doing, followed by better reporting.

Another solution appears to be the reframing of PI and the use of a multitude of different terms for collaborative working. These include participation, co-creation, coproduction and so forth. There are varying definitions of these terms globally and in different fields. This highlights the complexity of defining a way of working that has various aims, individuals involved, and contexts[92,210–212]. Occasionally these appear to be used synonymously, while at other times the terms appear to be distinct. It is, therefore, useful to explore how these terms are defined and how these definitions aim to tackle the issues surrounding PI.

"though we use the same words, the meanings that we give them can be very different."[211]

Previous sub-sections have shown PHCP working is a complex array of terms, actors, and, contexts, all of which influence how it is implemented and what it achieves. The following sub-sections explore the definitions in more depth and then move onto the impact of PHCP working.

2.2.4 Participation

Participation in international development is often associated with "the 'transformation' of existing development practice and, more radically, the social relations, institutional practices, and capacity gaps which cause social exclusion."[213(p13)]. There is evidence in the NHS of the term participation being used to mean PI, without a clear distinction between the two[189,214]. However, the term participation has a rich, although equally nebulous history in international development and there is debate about the extent to which it can, and does, realise this transformation[211,213].

The variation in practice is captured in White's (1996) descriptions of nominal, instrumental, representative, and transformative participation[210,211]. Nominal participation largely occurs to legitimise "the implementing agency"[210] - often the government or structural power[211]. Instrumental positions participation as a means to achieving cost-effectiveness. It is necessary for people to participate to realise this cost-effectiveness, but it may cost them to do so, for example in terms of the time taken from paid employment[211]. Representative participation gives local people a voice to achieve sustainability and enables them to influence development efforts[211]. Transformative describes the change that participation leads to in individuals, for example, by initiating collective action as a means to tackle injustices[211]. While providing a useful structure to describe participation then, White's work[211] and Cornwall's adapted typology[210] from this, show the term participation can perpetuate, rather than resolve, issues surrounding defining PI.

2.2.5 Coproduction or co-creation?

Coproduction is a term and concept that appears to be growing in popularity particularly in published literature. This may lead to some questioning as to why this thesis explores co-creation rather than coproduction, necessitating a brief exploration of the two terms. This is relevant due to the somewhat synonymous use of the two terms in the literature[92,93].

The meaning of coproduction varies depending on the level at which it happens. For example, Palumbo's (2015) systematic review of co-creation and coproduction in healthcare describes the one-to-one relationship between the public and HCPs to manage healthcare at the micro-level[93]. At the meso-level, this could relate to the design and delivery of healthcare interventions aimed at supporting individuals or collective health needs[93]. Overall then, "the health care system should be conceived as a co-producing service system, where both the providers and the patients are thoroughly engaged in a co-creating partnership"[93]. This is corroborated by Batalden et al.'s (2015) assertion that the public and HCPs always coproduce healthcare services "in systems that support and constrain effective partnership"[215].

Literature from marketing and business provide further insight, including into the relationship between co-creation and value. Palumbo (2015) described a nuanced distinction between the terms coproduction and co-creation, with the former meaning the partnership or relational aspects of how the public and HCPs work together[93]. Co-creation describes the way the public and HCPs work together to co-create value[93]. Voorberg (2015) concurs that this relationship to value was the fundamental distinction in the literature in the use of the terms coproduction and co-creation[92].

Additionally, the active participation or involvement of individuals is said to be a fundamental part of coproduction and co-creation[82,92,216,217]. Lusch and Vargo (2014) state the terms co-creation of value and coproduction are related but distinct. They see the former as part of the latter, yet they state co-creation of value always happens while coproduction is optional for the actors involved[217]. Specifically, coproduction occurs when actors actively participate throughout the value creation process. For example, patients being involved in co-designing services would be coproduction. Thus, PI in healthcare would be coproduction according to

Lusch and Vargo (2014). In marketing however, co-creation is described as an active process in its own right therefore challenging Lusch and Vargo's definition (sub-section 2.4.3).

Further challenge to these definitions come from Bason (2010) who distinguishes between co-creation, which focuses on creation, and coproduction, which focuses on production[87]. Specifically, "co-creation is about the development… of new solutions *with* people, co-production is about the leveraging of people's own resources and engagement to enhance public service *delivery*"[87(p157)]. This definition provides a useful distinction but could also highlight potential overlap if, for example, new solutions were created with people for service delivery.

Some argue "co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and neighbours"[94]. This is echoed by coproduction researchers and practitioners who emphasise the importance of shared power and the potential of equalising relationships[91,218,219]. In practice however, this may not always be the case and consultation on research topics could, for example, be labelled coproduction[220]. Practitioners therefore challenge those who work in organisations as not always willing to embed truly equal partnerships and caution "patient involvement is not coproduction"[219]. Therefore, while PHCP partnerships may influence healthcare design and delivery, they may not always be coproduction.

The literature does not appear to reach a consensus regarding definitions, and yet some feel having clear definitions forms an important aspect of being able to assess the impact of PHCP working as is discussed in the next sub-section[221–223].

2.2.6 What is value and how is it created?

Value is a complex term and means different things to different people. How value is seen varies depending on the discipline defining the concept. Graeber (2001) explores sociological, economical, and political definitions, concluding that value is "the way actions become meaningful to the actors by being placed in some larger social whole, real or imaginary"[110]. Value is defined as "what buyers are willing to pay"[224] in business terms, and in marketing terms by the formula 'benefits-cost'. In this context, businesses produce goods or services that have inherent value which is passed down to customers[224,225].

Perhaps because of the neoliberal influence[95,181], value in healthcare has largely been defined in economics terms such as "outcomes relative to costs"[67]. This can emphasise an importance of outcomes above processes. For example, a national programme exists to support and promote patient reported outcome measures[226], but there is no similar national programme to measure processes. Critiques of this economic definition state it misses crucial elements elucidating the benefits to the wider health system[227]. Moreover, conceptualising value in economic terms perpetuates models that aim to realise 'competitive advantage'. Goods or services sell for a lower price than competitors, or their unique selling point allows them to achieve a higher price, thereby realising advantage over competitors[224]. This creates dynamics which puts the onus on businesses to create value 'for' customers[224,228] or patients[67], rather than with them. Competitive advantage therefore frames value in a way that appears at odds with the collaborative nature of PHCP partnerships[229].

An alternative approach to realise competitive advantage saw value creation as a collaborative process. Value is said to be coproduced, with and by, various actors in a constellation[225]. This approach positioned customers as key actors along with suppliers, producers, and so forth, in a value creating constellation. It stated value was created in the relationships between businesses and customers, and that businesses should aim to "mobilize customers to… create value *for themselves*"[225(p69)]. The approach reframed the role of customers in value creation from passive recipients of value created by businesses, to active co-creators[82,225]. This mirrors the drive in the United Kingdom to involve patients and the public to modernise and improve the NHS[17,230], and aligns with efforts to incorporate patients or people, and especially their experiences, as core facets of value definition[227,231]. It echoes a global movement to position citizens as "makers and shapers"[75] in the communities they live and value co-creators of healthcare[34]. Value co-creation appears then, to have cohesion with patient and public-healthcare professional partnerships and could offer a useful lens to further explore and assess these partnerships.

2.3 Assessing Impact of Public Involvement

Whether and how the impact of PI should be assessed can be influenced by its conceptual underpinnings. Participation and involvement are already established as legal rights internationally and domestically[6,8,Art12 232] and can, therefore, be argued to be part of an intrinsic democratic process regardless of what they achieve. However, Beresford (2002) demonstrates the shortfalls of this viewpoint stating that just because involvement is a democratic right, it does not mean all publics are equally (able to be) involved[233,234]. This can perpetuate the concept of PI as “an intrinsic good”[161], which other research has stated should not be seen as a reason to not evaluate its impact[103]. The debate, therefore, shifts from whether the impact should be demonstrated, to how this way of working should be evaluated[43,102,104,105,235–237].

There have been recurrent calls highlighting a need to strengthen the evidence base of PI[42,43,104,107,235,238]. Staniszewska et al. (2008) argue the “lack of an evidence base can mean [PI] is seen as relatively low status and labelled as an ‘add-on’”[102]. They call for an evidence base showing how PI happens and the influence it plays, which will build a business case securing strategic commitment for PI[102]. Research highlights limited articulation of theoretical foundations[104], which if explicitly communicated can explain what worked in practice and how to increase the likelihood of achieving this again[126,239]. Assessment and articulation of the connection between context, processes, and outcome of this way of working can increase the likelihood of achieving meaningful and useful PI[23,108,240,241]. Yet literature focuses on PI outcomes more than mechanisms[242] or impact[235], and evaluating PI and assessing its impact remains absent or difficult[23,103,107,241,243].

Many have commented on the difficulties of evaluating and assessing the impact of PI in research, with more limited exploration of this in implementation. PI is a complex, nuanced, and relational process and it is difficult to assess which of its parts influence the outcomes achieved[103,107,244]. Some researchers view PI as a complex intervention[238]. They argue learning about how to evaluate complex interventions provides useful insight to assess the impact of PI, and specifically, that this framing could enable and advance its meaningful measurement[238]. This fits into a bigger debate about whether to measure the impact of PI[102,105,237]. Arguments against measurement question whether this agenda is driven and influenced by dominant approaches in evidence-based medicine including hierarchies of evidence[105]. However, Edelman and Barron (2016) argue evaluating PI like a complex intervention against pre-determined outcomes and using “unsuitable” approaches such as realist evaluation can lead to difficulties in assessing its impact.

PI evaluation frameworks and tools have been created in an attempt to enable more widespread evaluation[50–52,90,245]. Staley (2015) cautions against evaluating involvement if all this does is find the same impacts[105]. She describes recurring evidence reviews years apart that illustrate the same impacts of PI on the research process, for example, and argues understanding *how* the impacts or outcomes are achieved is far more relevant[105]. This is because the impact of PI is dependent on the context in which it happens and, therefore, understanding *how* through the context, mechanisms, and outcomes enables more generalisable findings[105]. However, it is not always clear what PI means, nor easy to predict how it will manifest[241], which limits the use of process evaluations[107,244].

Amidst this debate and discussion about how to measure the impact of PI, an alternative proposal has emerged to explore its 'value' as detailed in the next sub-section.

2.3.1 Exploring Value and Public Involvement

PI impact remains a nebulous term and evaluation remains an elusive process as discussed in the previous section. The ongoing debates around the impact of PI and how this can be assessed has led some to explore alternative approaches.

Some research describes the value of PI as being linked to improved experiences. Levitan et al. (2018) assessed the financial value of PI on the design and conduct of clinical trials and demonstrated a 500-fold return on investment[246]. The authors found PI led to improved experiences of the trial conduct resulting in, for example, fewer people dropping out of the trial[246]. Patients' engagement could therefore, reduce waste by co-designing a better trial experience for participants. This somewhat echoes Smith's (2016) research exploring PI through, and in, the use of Lean, a QI approach, to reduce waste and improve people's experience in an endoscopy unit[113]. The approach brought together the public and HCPs through a structured process that resulted in improved efficiency, increased bed-capacity, and a unit that took into account "patient preferences"[113]. The public then become necessary co-designers and co-producers of such systems, and thus a crucial first step of the process is to define value *with* them[247,248].

Some literature explores expanding articulations of value largely in people's own care, and suggests working with patients to understand what value means to them and to ensure efficient healthcare practice[68,80,99]. One considered definition that positions the public more broadly in the process of value creation, and as the definers of the outcomes, arises from the Realising the Value programme. Redding (2016) describes value as that which is "experienced and created by people and communities"[81] and proposes five ways the articulation of value should be broadened. Firstly, value should focus on the impacts on wider health and wellbeing and not just on specific clinical outcomes[81]. Secondly, the definition should explore what people and communities most value including outcomes, but not limited to the aspects the system values such as costs and value for money. Third, the articulation should go beyond patient experience to incorporate broader aspects of wellbeing. Fourth, rather than focusing on immediate outcomes from a specific treatment, the articulation should encompass outcomes over time, across multiple services and support mechanisms. And fifth, the articulation of value should move beyond "individual outcomes for the person" to more equitable realisation of health and wellbeing[81]. While this provides a useful and potentially all-encompassing definition of value in healthcare, it would be interesting to further understand its practical implementation and implications, both of which are beyond the scope of this study.

The literature exploring the value of PI at the healthcare systems level remains scant. The evidence that exists has shown that if healthcare professionals value PI they are more likely to use multiple methods to implement it[194]. Conversely, Snape et al.'s (2014) research demonstrated under-valued PI leads to tokenistic practice and underpins the perception that it is "not adding value to health and social care research"[103]. Their research evidences a connection between concepts such as 'intrinsic value' or 'added value' and PI in research[103]. This builds the potential of exploring 'value' when assessing or exploring the impact or "potential impact"[103] of PI.

McKevitt et al.'s (2018) more recent research further expanded and tested the concept of 'value' when examining the impact of PI in major systems change. Their study showed PI was perceived to have had value even though there was no evidence of its influence on major transformational change[77]. They found three types of value demonstrated by PI in their study: managing agitation, verification, and substantiation[77]. Agitation related to the public helping manage tension between HCPs[77]. Verification related to proactive PI that provided a mechanism to "anticipate and manage any dissent" and verify the plans for the proposed changes to healthcare delivery[77]. And substantiation related to having patients physically present to serve as a reminder that they were being involved and that the improvements being made were also for them[77].

Yet there is still much to be learnt about the value of PI or how it *adds* value, supplementary to a traditional health economics approach[107,249]. Research demonstrates discrepancies between what patients and HCPs perceive as value[99]. It has been argued that health and care systems "will need aligned concepts and frameworks for achieving and measuring value"[80].

This includes understanding whether the realisation, experience, and creation of value can help PI realise its transformative potential[77,249]. But also more fundamentally, assessment is needed to explore whether the value of PI can inform the bigger debate about its impact[77]. Indeed, McKevitt et al. (2018) conclude "investigating how value is produced—and for whom—through involvement might offer a way of rethinking impact assessment in involvement"[77].

Could explorations of value from the business world provide a way to do this? The next sub-section introduces a concept called 'value co-creation' that may offer a potential approach.

2.4 Value co-creation: An explanatory theory?

Value co-creation (VCC) stemmed from explorations into more collaborative value creation[225]. It still aimed to achieve competitive advantage[82] and is therefore framed by a neoliberal agenda. However, it acknowledged a more complex understanding of what value is and how it is realised[82,250]. It also positioned customers as active value creators rather than passive value receivers[82]. Value co-creation was proposed as a potential theoretical framework to facilitate successful partnerships in healthcare systems that in turn optimise the value realised[76]. VCC has been proposed and applied as a theoretical and conceptual framework to examine patient behaviours and interactions or partnerships with healthcare professionals or providers in their own care[251–254]. I now turn to a more in-depth exploration of value and its co-creation to understand its potential and pitfalls.

2.4.1 Value co-creation

Value co-creation (VCC) is a vast and varied field that sits across numerous disciplines such as innovation, marketing, strategy, and service science. The field in which VCC is situated has influenced the underpinning theories and approaches taken. While VCC continues to evolve, its pioneering works came almost in parallel from the fields of service science (through Service-dominant logic) and marketing. This was to explain a new wave of businesses which were creating value with various actors on constellations[82]. There is some consensus in both fields that sustainable, innovative companies create advantage over other businesses by co-creating value *with* customers[82,86,250]. Value is then created, extracted or realised through this collaborative 'co-creation' process[86,87,89,250] between various actors in a network[82,250]. However, the key authors in Service-dominant logic (Vargo and Lusch, 2004) and marketing (Prahalad and Ramaswamy, 2004) vary in their fundamental approaches to value co-creation[82,250].

2.4.2 Service-dominant logic: Value through services

Service Dominant Logic is a part of service science and describes a shift from a goods-centred to a service-centred view[250]. Lusch and Vargo describe traditional business models creating and selling goods and realising value for companies[217,255,256]. Their first "axiom" of value creation in the service dominant logic field is that competitive advantage over competitors is achieved through an exchange of services rather than goods[217]. Service relates to "intangibles, specialized skills and knowledge, and processes (doing things for and with)"[250]. Value then shifted from being inherently in the goods to being the result of how these are created or used through the exchange of skills and knowledge of the co-creators (the customer and the firm)[84,217,257,258]. This leads to Vargo and Lusch's second axiom which positions the customer as the constant co-creator of value[217]. For example, the value of a car is not in the product but rather in the fact that it provides a family with a "personal transportation service"[217]. Similarly, healthcare medications could create value not because of the product but through improving people's quality of life and their ability to be active citizens. These examples show that value, according to Lusch and Vargo, is realised when the items are in use.

The third axiom is "all economic and social actors are resource integrators"[217(p54)] and places all actors in an ecosystem of value creation. They are all necessary actors within the exchange of service and continue to create "resources by combining resources with other resources"[217(p75)]. The value creation ecosystems stress the importance of relationships and collaborative interactions to co-create value, especially since the fourth axiom states "value is always uniquely, phenomenologically determined by the beneficiary"[217(p54)]. For example, one person may use a smart phone simply to call people, while another may use it to monitor their health condition and upload the related information to their medical team. The medical team in turn may use the data for research or to improve how they help people manage their specific conditions. Thus, all actors contribute to combining resources to realise what they deem value.

A key challenge to applying this service science approach to VCC comes from its foundational principles which have evolved many times[257]. This makes it difficult to apply service science VCC as a framework to explain or assess. Indeed, these foundational principles are stated to be axioms rather than a theoretical framework[259]. They are challenged as not going far enough to explain the interactional aspect of value creation[258]. This is where the next approach to VCC may offer more potential.

2.4.3 Marketing: Co-creation as an interactional process

Prahalad and Ramaswamy (2004) provide an alternative prospect of VCC as an interactional process among individuals and between these individuals and the surrounding systems and structures[82,86,88]. They continue to position the customer as co-creators of value[82,260], and state these interactions are the "locus of value creation and value extraction"[89]. Ramaswamy (2011) emphasised value should be defined as human experiences as opposed to being realised in use through service exchange as described in the previous section[261]. Value is realised through personalised experiences, thus it is important to enhance relationships and environments that construct these[82,89]. Ultimately, high-quality interactions are fundamental to improving and personalising people's experiences thereby realising value for them and the business[86,88,89].

A patient with a pacemaker is provided as an example of the application of the theory of VCC in healthcare. Prahalad and Ramaswamy (2004) state value in such situations is created by a constellation of various actors, rather than the product (the pacemaker) alone. "Purposeful interactions"[82(p10)] between the actors, for example the healthcare professionals, family members and others, and places such as a scan and diagnostic clinic, collectively shape the patient's experience[82,89,262]. These interactions, specifically the experiences gained through these interactions, bring value[82,89,262]:

> *"…the experience is the result of the degree of patient involvement in the total process… The real value lies not in the pacemaker per se but the overall experience of that patient."* [262(p172)]

Value will be optimised for the person with the pacemaker by enabling high-quality interactions between individuals and places such as the clinic, and by facilitating personalised experiences.

A central tenet is creating high-quality interactions, thereby improving relationships and experiences to increase the likelihood that value is realised[85,86,88,89]. Dialogue, Access, Reflexivity[2] and Transparency (DART) are presented as the building blocks for co-creation,

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[2] Risk assessment in Prahalad and Ramaswamy (2004) but has since evolved to Reflexivity

providing a way to build purposeful, high-quality interactions[82,86,88,89]. Such interactions are complex because of the various individuals and systems involved, and DART provides a framework to manage this social complexity (Table 1).

Table 1 The components of co-creation as defined by the DART model

	Definition based on Ozcan & Ramaswamy (2014)[86]
Dialogue	Between equals through active conversation & sharing views of what is meaningful to individuals.
Access	Gaining information about experiences, context, tools, expertise, skills etc. of other agents.
Reflexivity	Achieving better co-creation by feeding back learning from co-creators, and structures that facilitate co-creation.
Transparency	Visibility of information. Implies openness and communication that builds trust.

The strength of DART comes through the interrelationship between the components. Dialogue between a healthcare professional and a patient coupled with access to information could facilitate reflexivity about the patient's health condition.

Furthermore, Ramaswamy and various colleagues state platforms are needed to facilitate engagement[86,109]. Engagement platforms are purposefully designed assemblages of Artefacts, Processes, Persons and Interfaces (APPI)[86,88]. These platforms engineer interactions and are key to initiating (co-creation) experiences where companies and customers interact[86,111]. Artefacts are "physical and digitalized things"[88] including data, heart-rate monitors etcetera. Processes include digital or business processes[88] such as those used for day to day healthcare delivery. Persons are the most important component[263] of these platforms and include companies, customers, employees and individuals as part of the wider related ecosystems[86,88]. Finally, "interfaces include physical and digitalized means by which an entity comes into interaction with another entity"[88]. In healthcare, engagement platforms could be ward rounds (processes) where teams of HCP come together at the patient's bedside (persons and interface), reviewing the patient's records (artefacts).

Value co-creation has been positioned as having transformational potential both within institutions, and in and for civil society[85]. This is through its ability to “change identity of the system we live in and the quality of our human experiences”[85(p223)]. Ramaswamy and Gouillart (2010) provide an apt example of the South Korean government’s initiative to establish significant and sustained engagement with their citizens[85]. Citizens could provide suggestions for improvement through the use of an online platform and other citizens could also comment on these suggestions. The relevant parts of the government explore feasibility of these ideas and feed back their findings. A group of prequalified participants, including citizens who use the online platform, then participate in an online discussion to assess the idea. Eventually, a public meeting is held with citizens, including those who proposed the idea and those active on the online platform, external experts, city officials, and nongovernmental organisations. The ideas proposed are debated and assessed for their potential suitability for adoption, with successful concepts being taken forward. Ramaswamy and Gouillart (2010) demonstrate a change in relationships between institutions and individuals towards more bilateral interactions aiming to transform society and “the human experience”[85(p246)]. They assert “the single most important shift that leaders must make is to recognize the centrality of individuals… and their human experiences as the new basis of value creation”[85(p246)]. As such, they establish value co-creation as both a theory and practice that is centred on interactions and therefore transferable beyond the business setting.

The transferability of VCC comes from the emphasis of it as an interactional process. Ramaswamy and Ozcan (2018) define co-creation as “enactment of creation through interactions”[88] and the combined literature on the construct position its focus on individuals as co-creators of value[82,86,111,261]. Rather than value being specific products the focus shifts to the “experienced outcomes”[88]. The experiences of co-creation and the co-created experiences become equally important, connected aspects. This focus enables VCC to transcend beyond specific contexts, providing a transferable theory and practice.

This transferability is further strengthened by the theoretical grounding of VCC using Deleuzian assemblage theory[264] and positioning it as a sociomaterial practice[265]. Prior to 2018, Ramaswamy and colleagues VCC could be argued to be an empirically-grounded construct that was under-theorised, but this was strengthened through connectivity with assemblage theory and sociomateriality[88]. Assemblage theory provides a way to describe and establish VCC as an interplay between structure and agency that goes beyond micro and macro level categorisation[88,264,266]. The theory focuses on connections and relationships as more accurate descriptors of the world and being[264,267] that provide a way to navigate social complexity[264,268]:

> "This is because assemblages, being wholes whose properties emerge from the interaction between parts, can be used to model any of these intermediate entities: interpersonal networks and institutional organizations are assemblages of people; social justice movements are assemblages of several organizations; cities are assemblages of people, networks, organizations, as well as of a variety of infrastructural components, from buildings and streets to conduits for matter and energy flows; nation-states are assemblages of cities, the geographical regions organized by cities, and the provinces that several such regions form."[268(pp5-6)]

Crucially for VCC, parts of the assemblages connect and interact and become greater than the parts, but are also autonomous, independent 'wholes' in their own right and can become parts of other assemblages[88,264,266,267]. The interactions through which varying assemblages are formed or network, and the constellations that emerge become key factors[266,268] for the "interactional creation of value"[88]. Assemblage theory therefore underpins the interactional element of VCC.

Orlikowski and Scott's work on sociomateriality furthers solidifies the crucial elements of VCC[88,265]. Their work describes the intersection of technology, work and organisation which they see as interrelated rather than distinct categories in practice[265]. Orlikowski and Scott argue that sociomateriality concerns the interactions between human and non-humans and their connected design, relations and boundaries, and brings together multiple underpinning theoretical approaches[265]. Sociomateriality then provides the theoretical foundations for the design of the VCC engagement platforms explaining the combination of APPI[88], which facilitate interactional creation. These multiple theoretical foundations then strengthen the interactional aspects of VCC and go beyond context.

2.4.4 Value co-creation in healthcare

Application of VCC in healthcare tends to come from the Service-dominant logic arm and relate to patients' involvement in their own care. Since Service-dominant logic positions everything as services, this arm of VCC may be deemed more applicable to healthcare. Some of these works conceptualise the potential of VCC or provide research frameworks for its application to improve healthcare for individuals[251,253,269–272]. Other studies are empirical and apply Service-dominant logic VCC to improve healthcare for patients receiving care[100,273]. This includes significant longitudinal research on this arm of VCC from McColl-Kennedy and colleagues that provide empirically-based conceptualisations and more detailed typologies of co-creation practices[254,274,275]. Their work describes roles and activities that underpin 'customers' co-creation practices[274,275]. They empirically demonstrate the importance of interactions for individuals to co-create value[100,275], and describe how VCC can explain people's passive compliance versus active engagement of their health conditions[254]. VCC has been used to understand how value is defined by patients and carers. This research shows even if the value realised is relatively low for them in that instant, it can lead to value for other individuals or parts of the healthcare and related system[100,276,277].

McDermott and Pederson (2016) state value co-creation could offer a framework to explore the public's motivations in shaping service delivery and improvement[278]. They demonstrate the importance of the relational aspect of interactions between the public and HCP, and call for further research to make these aspects explicit. Further evidence for this comes through explorations of co-creation from non-healthcare settings. Bason (2010) states co-creation with citizens is a fundamental part of a public sector innovation ecosystem[87]. He argues citizen involvement provides necessary insight to co-create responsive and useful innovations[87]. Nambisan and Nambisan's (2013) work goes further and states effective co-creation is achieved through roles for individuals and surrounding, supportive ecosystems that facilitate this way of working[279]. In healthcare, Nambisan and Nambisan's (2009) work describes partnerships between HCP and the public as one of the ways the latter can improve healthcare planning or create new products[280]. And more recent work has positioned VCC as providing potential to optimise collaborative working, and thus value realised from public and HCP partnerships to shape healthcare[34,76,271,278].

There is scant use of Ramaswamy and colleagues' VCC in healthcare settings. The literature that exists tends to favour application of the DART model to explore individual engagement in their own care or hospital-provider co-creation[281,282]. Existing research has started to uncover the dynamic nature of public and HCP interactions[59,283]. Ramaswamy and colleagues' work could offer a complementary perspective on how these interactions are created, and their existing research demonstrates the importance of interactions realising value for patients with pacemakers[82]. Janamian et al. (2016) provide a rare placement of the DART model as a way of embedding a co-creational culture where healthcare providers and the public "become equal partners, focused on the issues of interest to both"[34]. Additionally, Greenhalgh et al. (2017) stated that this arm of VCC, and their focus on engagement platforms in particular, offer promise for these author's own prospective study of improving partnership-working in healthcare[76]. To date this remains the closest, published work that connects using VCC to improve healthcare systems.

2.5 Conclusion

There remains great debate about how to assess the impact of public involvement in healthcare. The evidence shows this is more complex because of the varying nature of public involvement, its divergent conceptual underpinnings, and the different processes and contexts in which it happens. The literature reviewed demonstrated added complexity through how the public have been involved in healthcare improvement and specifically QI efforts. This setting differs from public involvement in health research, and evidence has demonstrated this context influences public involvement in unique ways and warrants further investigation[114]. Some of the existing research of public involvement in healthcare improvement comes from the perspective of researchers [for example 78,114,192,284]. Although there is evidence of some practitioners shaping some of this research [for example 57], this remains scarce. It would therefore be useful to research PHCP partnerships from the perspective of a practitioner who has experience of supporting and facilitating this way of working in the healthcare improvement sphere. This perspective may offer insight that could help bridge the gap between the research that is conducted and its impact on future practice.

This chapter discussed the issues and potential solutions to realise value from PHCP co-creation, through the presentation of literature from three broad fields: healthcare improvement and quality improvement; public involvement, and value co-creation. There are four main interrelated gaps in the literature that this thesis will investigate.

The first gap relates to how to optimise public involvement in healthcare improvement and enable it to reach its transformative potential[55,78]. The research cautions the need for "careful management" of public involvement to enable it to influence improvement[78]. Furthermore, literature shows how some see the public as an important part of healthcare improvement, yet they are not always part of the process[25,194]. Some have suggested value co-creation could provide a useful approach to improve partnership working which includes with the public as a mechanism to improve healthcare[34,76,82,271,278]. This includes through the use of platforms for engagement and the DART model as created by Ramaswamy and colleagues[34,76,82,86,271]. Yet there is no empirical exploration of value co-creation for PHCP working in healthcare improvement.

The second gap relates to Ramaswamy and colleagues' assertion that co-creation is an interactional process[82,86,88]. They connect this process to what is achieved, therefore an optimised interactional process will increase the likelihood that co-creation will realise value[82,85,86,88]. This therefore requires further research into the nature of public and HCP interactions. While some literature acknowledge the interactional nature of PHCP working, this remains scant[106,283]. Other research demonstrates the importance of further understanding more generally the relational aspect of how public and healthcare professionals work together[95,278].

The third gap concerns the continuing, fervent debate regarding whether and how to assess the impact of PHCP working. While there has been no 'silver bullet' solution, McKevitt et al. (2018) call for further exploration of the concept of 'value' as a potential approach to assess the impact of public involvement[77]. Yet, there remains scant exploration of value in public involvement literature and no prospective study of the value of public-healthcare professional partnerships.

The fourth gap relates to Renedo et al.'s (2014) findings that QI methods can facilitate public involvement[114]. Their findings were from one QI organisation and they therefore suggest other research across multiple healthcare improvement organisations to further test and explore this. Since my research will exploring PHCP partnerships in healthcare improvement organisations, it can provide empirical data to address this suggestion.

2.6 Research questions

The aim of this thesis is to investigate how public and HCP work together for healthcare improvement, and how this can be optimised. This includes in environments where a more structured approach to QI is taken that results in adopting specific methods such as those introduced in 2.1.2 and 2.1.3. But it also includes broader healthcare improvement (2.2.2) as captured by Batalden et al.'s definition of QI (2.1.1).

The literature review above shows the potential of value co-creation to further investigate the process of PHCP working and its impact. Since Ramaswamy and colleagues' arm of value co-creation has been proposed as a helpful theoretical framework to optimise partnerships in healthcare, it offers a useful lens through which to explore my overarching question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

This is then divided into the following sub-questions:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*
b. *What value is achieved through PHCP co-creation, and why is it deemed value?*
c. *How and why does the use of QI methods facilitate or impede PHCP co-creation?*

This study aims to make explicit the processes that underpin PHCP working and will contribute the first empirical application of Ramaswamy and colleagues' value co-creation[82,86] in healthcare improvement. In doing so, it will contribute to the evidence base of the impact of public involvement.

The next chapter presents the methodology and methods that will structure how this research will be conducted.

3. Framing this Research: Methodology, Design and Methods

This chapter sets out the methodology and methods of this research that explores PHCP co-creation in healthcare improvement. It introduces the factors that influenced the inception of this research, and the adoption of the participatory paradigm to frame this study. The paradigm positions a collaborative approach through which it aims to align research and practice. This has therefore influenced the design of this study and the methods adopted. I describe the research methods used and share reflections captured through the research process. I also introduce the contexts in which this research took place. I finally explain the theoretical framework and the data analysis process.

3.1 Inception of this thesis

> “Being embodied in the world is a condition of my philosophical voice. It is a voice that is located in, and a voice that is shaped by, a thick web of political sedimentations and other value-laden commitments. These introductory reflections, then, are grounded within my standpoint, my perspective, and my personal biographical location. I make no effort to do the impossible: to become invisible, apolitical, decontextual, to speak from nowhere.” Yancy 2002, cited in Sian[285(p1)]

It is impossible to discuss the inception of this thesis without making explicit my own journey to this point. In line with Yancy’s words above, and in the spirit and practice of other postcolonial and decolonial thinkers, and Black feminist thought, I place importance on *who* constructs knowledge, and *how*[286–288]. More specifically, this focuses on challenging epistemologies and methodologies that present specific realities of researchers removed from the subject, or people, they are trying to understand[286,289–291]. Collins describes her theorising of Black Feminist Thought as coming from “thought and action”[287(pix)], and through her reflection on her research topics while immersed in everyday activities:

> “Much of my formal academic training has been designed to show me that I must alienate myself from my communities, my family, and even my own self in order to produce credible intellectual work. Instead of viewing the everyday as a negative influence on my

> theorizing, I tried to see how the everyday actions and ideas of the Black women in my life reflected the theoretical issues I claimed were so important to them”[287(pix)]

In an analogous manner, my personal and professional experiences have provided necessary opportunities for thought and action that have advanced my own theorising. These include the experiences and interactions my family, close friends and I have had with the healthcare sphere during my research, and my professional experiences as described in this sub-section. My journey has been instrumental to the methodology, design and methods of this research, and the theorising that has resulted.

This chapter therefore is an attempt to articulate the thought and action cycle that influenced the research journey and findings. As such, what follows is a reflective account that weaves together the interactions and experiences that enabled and influenced this study.

About me

Throughout my career I have created partnerships to enable more effective working. I worked in the international development and human rights sphere from 2003, including in India and Sub-Saharan Africa. I saw passionate civil societies protesting for, and achieving, change. This highlighted the potential power of people and communities, and inspired me to continue working as a practitioner-researcher for grassroots organisations. I saw real change could be achieved at the grassroots level. In my experience, grassroots organisations were passionate and solution-focused but had limited resources and reach. Partnership working with local populations or other organisations could be a functional method of realising more than could be achieved in silos. While there is a perception that international development employs partnerships well, this was not always the case in practice. Efforts were needed to make partnerships work.

I joined the NHS in 2008, analysing and reporting on patient experience, and facilitating patient and public involvement in a primary care trust (PCT). The PCT was seen as a pioneer in these areas, even though I struggled to see the novelty in what we were doing. This was not because it wasn’t useful or ‘good’, but because it seemed logical. Again partnership working, in this instance between the public and HCPs, was not everyday practice.

Initiating this PhD

I initiated this PhD during my role with CLAHRC Northwest London. This role introduced me to the world of healthcare improvement and highlighted specific approaches that could be used for this field. Many of us who worked at the organisation positioned collaborative working between the public and HCPs as a core principle for healthcare improvement[292]. However, we saw that this way of working was still not everyday practice in healthcare. When it did exist, it was questionable whether it always achieved more than could otherwise be achieved. My position between the worlds of improvement and involvement practice provided a unique lens to further explore how we improve PHCP working. Specifically, could methods and approaches from improvement strengthen and support more effective involvement? Informal testing in our own work showed some QI methods could offer a reflexive approach to improving involvement. However, more research was needed to further explore this.

This research aims to bridge the gap between theory and practice replicating my own stance as a practitioner-researcher. It aims to explore how and why PHCP partnerships work in practice. This study hopes to produce some generalisable findings to help public and HCP practitioners engineer and optimise their partnerships. This was crucial to the paradigmatic approach taken, the research questions, and my own position as an "inside learner"[293].

3.2 Methodology

This section introduces the participatory paradigm and qualitative inquiry which framed this research.

3.2.1 Participatory Research Paradigm

There are multiple research paradigms that describe ways of viewing the world (ontology) and have views on the way of knowing (epistemology). These paradigms ultimately frame a researcher's approach:

> "A paradigm is a world view, a general perspective, a way of breaking down the complexity of the real world. As such, paradigms are deeply embedded in the socialization of adherents and practitioners: paradigms tell them what is important, legitimate and reasonable" [Patton, 1978 cited in 294].

These paradigms influence how and why researchers use specific strategies to carry out their research[293] including the methods they see as appropriate. These paradigms are evolving rather than static as research adapts and aims to explore different or new phenomena[295,296]. The participatory paradigm has been an example of this paradigmatic evolution. Extensive reflection and consideration led to the participatory paradigm framing this research.

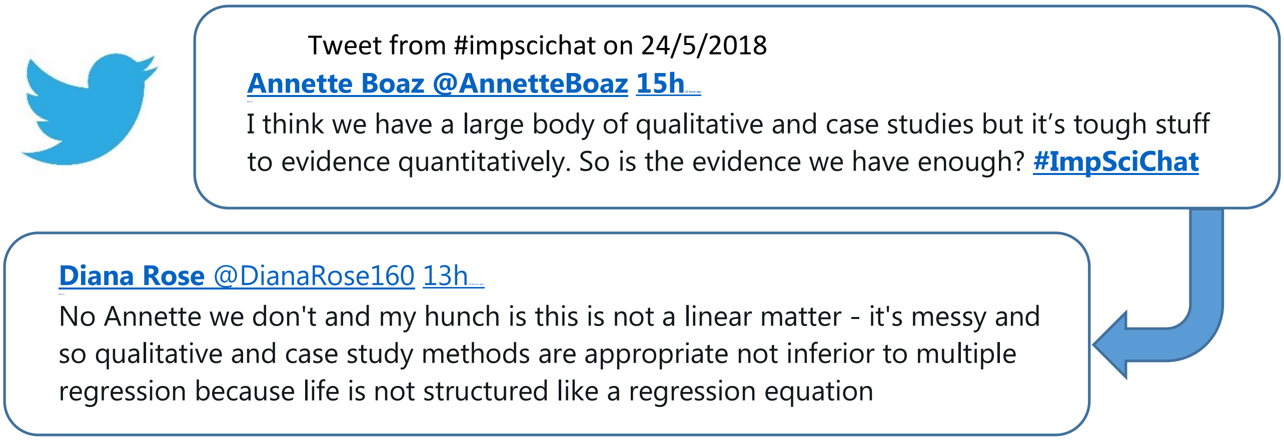
The participatory paradigm sees researchers as participants in the world rather than objective observers. Knowing and learning is therefore grounded in the experiential and is connected to this participation. Heron and Reason (1997) say the participatory paradigm is grounded in "four interdependent ways [to know and articulate the world]: experiential, presentational, propositional, and practical"[295]. Experiential knowing is learning by doing[296] and "knowing by acquaintance, by meeting, by felt participation in the presence of what is there."[295] This is central to the other three ways of knowing. Presentational knowing comes from processing the experiential knowledge through its presentation which, in turn, enables people to understand its significance[295,297]. Propositional knowing "is knowing 'about' something in intellectual terms through ideas and theories"[297]. Practical knowing is knowing "how to do something"[296], for example, through the skills, knowledge and experience[295] a nurse acquires in formal training and through their experiences in healthcare. All four of these ways of knowing are enabled through co-operative inquiry[295,298].

Co-operative inquiry aims to produce research that transforms practice, or repositions how we see the world. Such inquiry provides an alternative to research practices which position the researcher as the gatekeepers and creators of research. In such practices "people are treated as passive subjects rather than as active agents"[298]. Co-operative inquiry (formerly collaborative inquiry), therefore, aims to conduct research *with* people rather than about or for them[298]. It enacts a collaborative research enquiry through cycles of action and reflection[295,298]. A group of people are positioned as co-researchers. They come together and decide on the area of focus. They then, co-explore this area of focus and all co-researchers participate in repeated cycles of reflection and action. Heron and Reason state good quality co-operative inquiry in the participatory paradigm comes from "congruence" of the four ways of knowing (Experiential; Presentational; Propositional; and Practical) and the iterative, collaborative learning through cycles of action and reflection[295,297]. This inquiry may have potential to bridge the gap between research and practice.

The principles of co-operative inquiry and the participatory paradigm resonated with principles of involving and engaging the public to improve healthcare. It echoed directives encouraging HCPs and researchers to carry out research *with* and not for the public[38]. It also modelled the collaborative approach this thesis aimed to explore and optimise. It, therefore, seemed a sensible choice to frame this thesis.

3.2.2 Qualitative Inquiry

This research explores *why* and *how* PHCP partnerships worked in practice. These partnerships and surrounding contexts were varied and complex natural settings. These factors supported qualitative inquiry as a way of better understanding the phenomenon and the contexts[299,300]. This type of inquiry is particularly useful to shed light on the messy, less structured reality of life[301]:



Tweet from #impscichat on 24/5/2018

Annette Boaz @AnnetteBoaz 15h

I think we have a large body of qualitative and case studies but it's tough stuff to evidence quantitatively. So is the evidence we have enough? **#ImpSciChat**

Diana Rose @DianaRose160 13h

No Annette we don't and my hunch is this is not a linear matter - it's messy and so qualitative and case study methods are appropriate not inferior to multiple regression because life is not structured like a regression equation

3.3 Methods

This research was carried out through a combination of participatory and ethnographic methods which provided a more comprehensive, synergistic understanding of PHCP co-creation in practice. The participatory paradigm acknowledges the validity of including ethnographic methods for inquiry[296], thereby supporting the combination of these methods.

3.3.1 Participatory methods

This study aimed to embed adapted participatory methods to change how PHCP worked together and improve the impact this way of working had on healthcare improvement. Participatory methods were a natural choice for research framed by the participatory paradigm.

Co-operative inquiry lends itself to action research which mirrors the cycles of action and reflection. Kurt Lewin (1946) established Action Research as a fact-finding approach to challenge racism and prejudice against minority communities in America[302]. He positioned Action Research as a way to improve relations between the groups through "experimental comparative studies of the effectiveness of various techniques of change"[302(p37)]. This method aimed to provide an alternative to the dominant survey methodology of the time[302]. Lewin describes this method as a cyclical process shifting between planning an action, testing this in practice, learning about what happened, and planning modifications for the next iteration[302]. Lewin used Action Research to bring together communities with formal institutions, such as government offices, to make changes and improve inter-group relations[302].

Action Research has continued to evolve through its use and adaptation over time. It "has shifted from a scientific approach to social change to a more qualitative and social constructionist methodology"[303]. This method has been used in health and care settings to manage change in a collaborative and participatory way. Such changes include those across a ward or hospital, but also micro-level changes to how medications are administered[303]. Therefore, Action Research could be a potentially useful way to improve how PHCP worked together.

After much consideration and exploring relevant literature, I decided Action Research could provide a reflective method useful to make explicit iterations that aimed to improve PHCP working. It would, therefore, would form a small part of this study. The method would be framed by plan-do-study-act (PDSA) cycles as these echoed Lewin's description of Action Research[302], and existing research demonstrated the potential of PDSA cycles for participatory evaluation[142]. PDSA cycles originated in industry and provided a way of planning an intervention, testing this in practice, studying what happened and then reflecting on what could be done differently next time. This, then, builds into the next PDSA cycle test to support the change being made. These cycles are used in healthcare[145], including in the programme in which this research was conducted. The similarity of these and Action Research offered a pragmatic solution for how to enact a co-operative inquiry. PDSA cycles were a familiar tool to people involved in, or part of, this research, and would mean not having to introduce a new tool to guide the Action Research method.

3.3.2 Ethnographic approach

I was interested in the way ethnographic observations could uncover the reality of what people do, versus what they say. PHCP working is often mandated or strongly encouraged and HCP, in particular, may not be completely open about their views through interviews. Therefore, the ethnographic approach aimed to provide awareness of what actually happened in practice.

Ethnography has roots in anthropology and aims to understand a culture by being immersed in it. Howard Becker, in his study of deviance, stated:

> If [the researcher] is to get an accurate and complete account of what deviants do, what their patterns of association are… he must spend at least some time observing them *in their natural habit* as they go about their ordinary activities[304(p170)].

The strength of ethnography, therefore, comes from this learning through immersion in natural settings. These settings are not controlled, or artificially created. Therefore, the researcher is able to experience people's natural and ordinary practices, behaviours, and interactions as they happen in natural surrounding environments. This provides a "means of learning the explicit and the tacit aspects of their life routines and their culture"[305]. Such learning highlights the realities of practice and, therefore, provides a useful approach for inquiry into complex settings such as healthcare[306].

Ethnographic data are gathered through participation in a single setting or small number of cases from observations, conversations, interviews, and documentary data[307]. These multiple data sources enable researchers to build a richer understanding of the individuals and contexts they are studying over time[308]. Participant observations enable researchers to understand the realities of practice – what is done, as opposed to what may be said in an interview[309]. Informal conversations[308] can provide insight into lives outside of the setting that may impact behaviour in the setting. Interviews enable researchers to explore issues in further depth. Documentary data can provide useful contextual understanding. Data can, therefore, be gathered through informal and formal methods, occurrences, and conversations. For example, observations may take place in formal meetings, but also of informal corridor conversations. Ethnography then, is based on a culmination or triangulation of various methods in order to slowly build a richer, stronger picture over time[307,310].

Researchers may be keen to make the most of their participant observations since these are key to ethnography. However, this can be difficult because the researcher initially at least may be a "stranger" in the setting [Schutz cited in 308]. Spradley's (1980) guide is, therefore, useful to support structured familiarisation with a setting and guide participant observation[311]. Nine dimensions can be considered to guide the observations: Space; Actor; Activity; Object; Act; Event; Time; Goal; and Feeling[311]. Ethnography enables understanding gained through experiencing all these layers, with findings being uncovered and constructed throughout this immersive experience. Spradley (1980) highlights the cyclical, reflexive nature of ethnography[311]. Collecting observations is not something that starts and stops, but is an iterative process of gathering, reflecting, analysing, and probing[311]. This can continue even during the final write up of the ethnography[311].

Fieldnotes are used to make an ethnographic record of data that can be analysed. These fieldnotes form an account of the inquiry. They relay a level of detail that enables the researcher to refer back on their journey[308]. Fieldnotes may be covertly or overtly written depending on the situation and what is allowed or accepted in the specific setting[308]. Informal interviews - the conversational questioning that occurs through interactions in the field, are also included in these fieldnotes[311]. Hammersley and Atkinson (2007) state these "are always selective: it is not possible to capture everything"[308]. There are, however, pragmatic ways to structure this selectiveness. For example, fieldnotes could be framed by the overarching research question. Such data are also likely to become more focused over time, through the cyclical relationship between analysis, probing, and collecting further fieldnotes, and the researcher's increasing familiarity with the setting[311]. These fieldnotes, along with relevant other data from, or related to the field, form part of the ethnographic write-up.

A written ethnography aims to "translate"[308,311] the researcher's cyclical ethnographic journey for an external audience. This writing happens throughout the ethnographic process and is continually refined[311]. Geertz (1973) uses the term "thick descriptions" to define the level of detail that "sorts winks from twitches and real winks from mimicked ones"[312]. Thick descriptions are key to enabling others to truly enter the worlds explored through the ethnographies. Examples in healthcare settings include Becker et al.'s (1961) ethnography of the experiences of students in the somewhat elite medical school[304], and Allen's (2014) ethnography that uncovered the hidden work that nurses carry out[313].

Some may challenge the validity of ethnography as it is not value-free or objective. However, Hammersley and Atkinson (2007) respond by encouraging researchers to note reflections on their experiences during their ethnography[308]. Reflexivity then, is a core part of ethnography. This relates to the relationship between, and the implicit combination of, the researcher and the world they are studying[308]. Specifically, it "acknowledges that the orientations of researchers will be shaped by their socio-historical locations, including the values and interests that these locations confer upon them"[308]. Data sources including participant accounts, observations of practice, and documented accounts of the researcher's own reflection are triangulated to give a more complete sense of the ethnographic findings[309].

Another challenge to dominant anthropological and ethnographical research practises is that these can position the observed as 'others'. In one of the first accounts of freed Black slaves in America written by a Black person, Du Bois (1903) explains he is lifting "the Veil" between "the white world" and the one he describes[314(p5)]. As a Black person, he arguably explored the world of these freed black people from a closer vantage point than many of the previous accounts by White researchers. He goes on to describe the:

> …peculiar sensation, this double-consciousness, this sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity[314]

It could be argued then, that Du Bois's work brings a contextual understanding that is less likely to create stereotypes and label the people who are the focus of the research as 'other'. Mohanty argues the colonial roots of anthropology have caused this inherent issue that positions "the third world woman as "native""[315(p74)]. While there is use in people studying these unfamiliar cultures and environments, it is necessary to reflect on the assumptions we bring. It should be noted that wider prejudices can influence specific assumptions that establish ways of thinking not necessarily accurate or reflective of people's lives and behaviours[315,316]. This challenge is particularly important for my research as it is framed within the participatory paradigm.

Ethnography can be seen to be time-consuming. In response, rapid ethnographic approaches have evolved[317], some of which are more participatory[318]. These tend to spend less time in field and provided useful that can inform healthcare interventions[317,318]. Rapid ethnographic approaches therefore offered valuable potential for this PhD.

3.3.3 Case Study Method

I decided to use case study method to provide a deeper understanding through a smaller number of examples. This could help me understand factors that influence PHCP working where surrounding structures varied.

There are many definitions of cases. Stake (1995) refers to them as "bounded" or "integrated systems"[319(p2)]. An improvement initiative, QI programmes, or people can therefore be deemed cases[319,320]. An inquiry using case study method, therefore, is focused on elements the researcher sees as part of these cases, and they could be exploratory, explanatory, or descriptive[320]. Crucially, the case is investigated within its "real-world context"[320(p16)], and potentially problematically "the boundaries between phenomenon and context may not be clearly evident"[320(p16)]. Ultimately, some feel there is less need to define the exact nature of a case and more requirement to appropriately consider the use of case study research for the specific line of inqury[320,321].

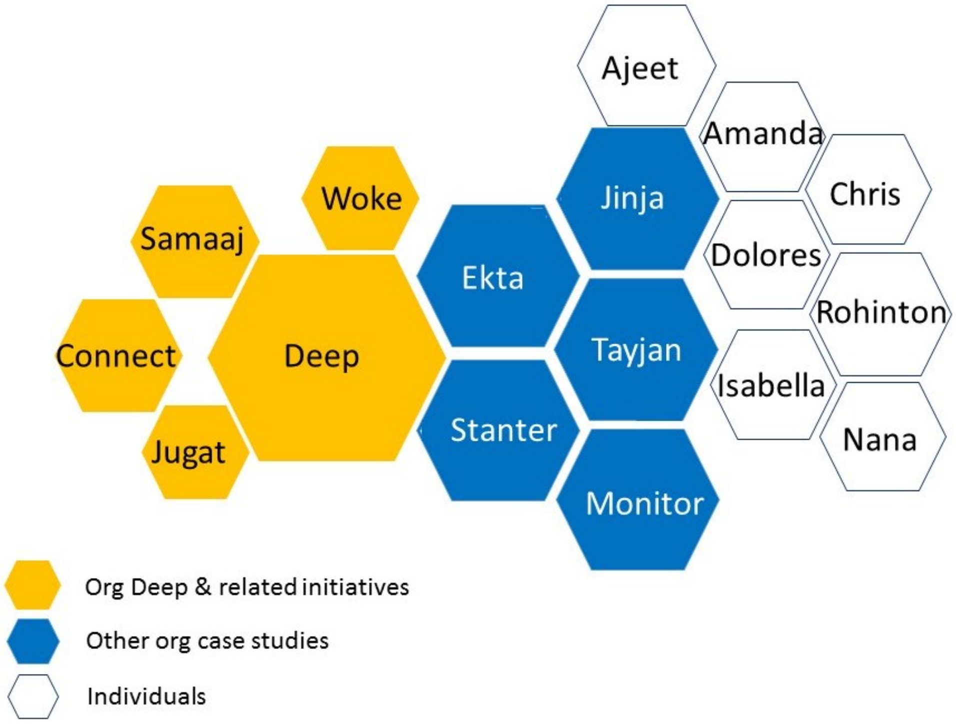
Various factors can influence why, and how, cases are selected. Stake (1995) describes intrinsic case studies as those chosen to provide information about the specific case[319]. Conversely, instrumental case studies are selected to provide insight for a line of inquiry or research question[319]. Inquiries may select single or multiple case studies[319,320] to provide insight from "both their uniqueness and commonality"[319(p1)]. Selection could be based on a desire to test existing, or create explanatory theories[320].

Some challenge the generalisability of findings from one study to other settings. Stake (1995) responds that the depth of understanding garnered through the evolving relationship between the researcher and the case enables generalisations[319]. These could be informative themselves or be used to modify existing grand generalisations[319]. Yin (2014) argues generalisations from case studies cannot apply to larger population groups[320]. However, analytical generalisations can be made that "go beyond the setting for the specific case"[320(p40)]. To support this, creating a theoretical statement or an explanatory proposition is crucial when designing case studies[320]. These are then refined as analysis is conducted from data within the case and across the cases (if multiple case studies are used)[320]. The statement or proposition is refined after each of these stages of analysis leading, eventually, to generalisations that can be made.

3.4 A brief introduction to the cases

A number of organisations and individuals were included in this research (Figure 2) some of which were included as cases, as described in this sub-section.

Figure 2 Organisations and individuals included in this research



One healthcare improvement organisation (Deep) was purposively sampled for in-depth exploration. This was influenced by its existing PHCP practice and because I worked at the organisation which, therefore, afforded me access.

Deep is a healthcare improvement organisation based in London, UK. They had won funding through a competitive bidding process from a national health research funder. This funding came with a remit to improve the translation of evidence into practice. Deep adopted and evolved a systematic approach to healthcare improvement which they felt increased the likelihood of success. This approach included a range of QI methods and a mandate for the public and HCPs to work together. Organisation Deep would, in turn, hold an annual competitive bidding process and fund and support a number of healthcare improvement initiatives. These initiatives were strongly encouraged to use the systematic approach. My research in organisation Deep occurred through longitudinal inquiry of PHCP co-creation in the organisation itself, as one case study, and through an additional four healthcare improvement initiatives that Deep funded. These four healthcare improvement initiatives also formed case studies (Table 2) because their boundaries were inherently different to those of organisation Deep. For example, these healthcare improvement initiatives were located in, or focused on, different organisations or geographies than Deep, and the individuals involved in them also had different remits that were often broader than service change.

Table 2 Case studies within Organisation Deep

Initiatives	Setting	Health condition	When studied?
Woke	Acute care	Medicines management	Retrospectively
Samaaj	Community	Endocrine disorder	Retrospectively
Jugat	Acute care	Cancer	Prospectively
Connect	Primary Care and Community	Chronic heart condition	Prospectively

The findings from the case study of organisation Deep were then tested against findings from the five other healthcare improvement organisations (Table 3). Additionally, seven interviews were carried out with public or HCPs that captured their experiences from other healthcare improvement initiatives across the UK but these were not deemed cases (explained further in C). These data were all triangulated to corroborate and test the generalisability of the findings that emerged from Deep. More in-depth information about the sampling, data collection, and so forth through these cases is explored in the forthcoming sub-sections.

Table 3: Six organisational case studies

Organisation	Primary Focus	Location	Research Phase[3]
Deep	Healthcare improvement	UK - specific geographic location	1
Ekta	Healthcare improvement	UK - specific geographic location	2
Jinja	International development	International	2
Monitor	Healthcare improvement	UK-wide	2
Stanter	Healthcare improvement	UK - specific geographic location	2
Tayjan	Acute care	USA	2

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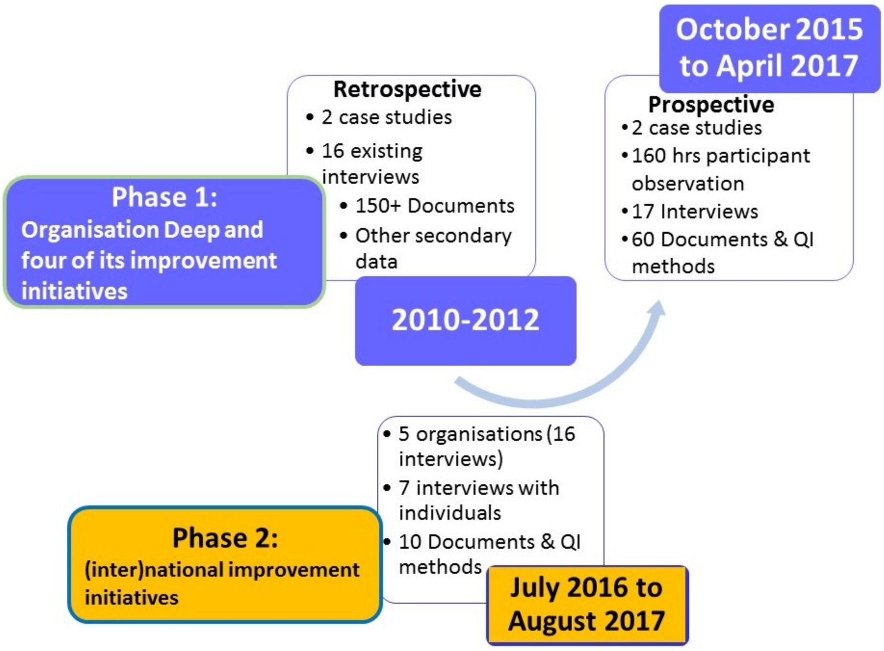
[3] Research phases are explained in sub-section 3.5

3.5 Research Phases

This sub-section describes the sampling and data collection in the two phases of research (Figure 3). Phase 1 aimed to provide comprehensive learning of PHCP co-creation in one healthcare improvement organisation (Deep). It specifically aimed to investigate any similarities or differences in the practical realisation of PHCP co-creation, and the outcomes this way of working achieved when the surrounding healthcare improvement context was relatively similar. Phase 2 aimed to describe the variations in how PHCP co-creation manifests across different healthcare improvement contexts. This phase aimed to explore the relationship between varied approaches to healthcare improvement and how PHCP co-creation happened in these organisations, and how PHCP co-creation was viewed and supported in different contexts. The combined analysis from both phases, therefore, provided a comprehensive and synergistic understanding of PHCP co-creation in practice.

Phase 1 research was conducted within organisation Deep. First, two improvement initiatives were studied retrospectively using secondary data. Then, another two improvement initiatives were prospectively studied through ethnographic and participatory approaches. Phase 2 was initiated during this prospective study, and collected data from five more organisational case studies. These were healthcare improvement-focused organisations in the UK and USA, and seven additional individuals who were not part of these organisational case studies.

Figure 3 Data collected from the two research phases



3.5.1 Triangulation

Triangulation is combining multiple methods to strengthen the findings in an inquiry. It is seen as an alternative to validation and a "strategy that adds rigor, breadth, and depth to any investigation"[300(p4)].

In this study, triangulation added rigour by providing avenues to test and refine findings, and informed the focus of investigations during data collection. Figure 4 shows how this triangulation occurred by data source[322,323], and by methods[322]. The triangulation by data source occurred because the research was conducted in different organisational contexts, and through the perspectives, observations, and practices of different people (the public and HCPs). These investigations also took place in different places (hospitals, community settings etcetera).

Figure 4: Combination of methods

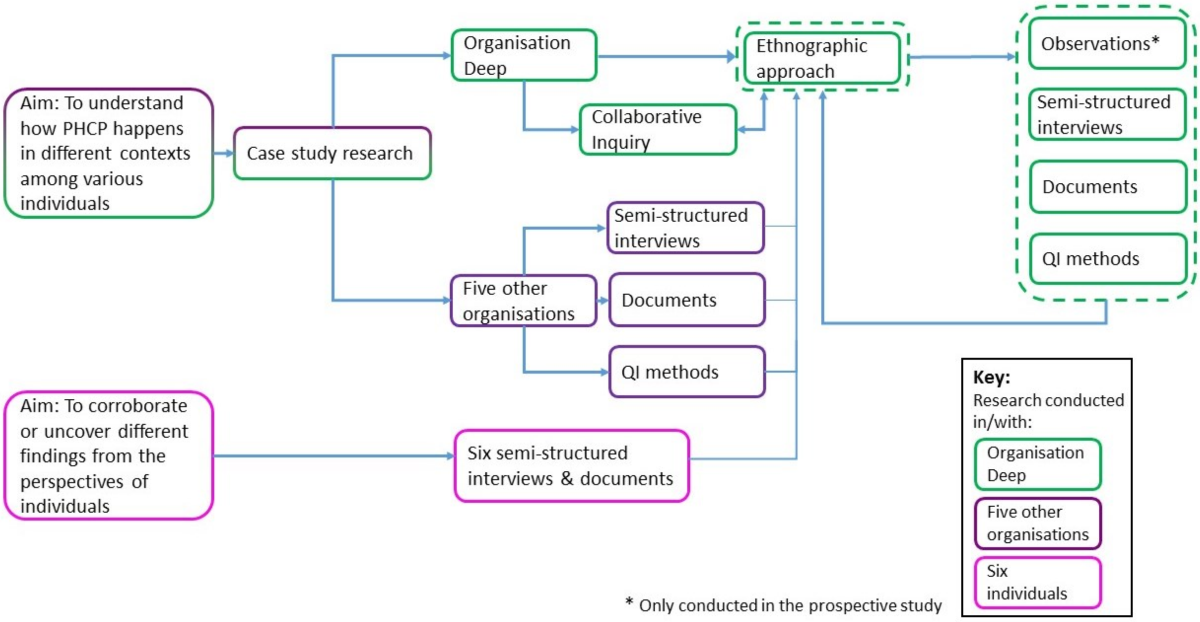


Figure 4 also shows triangulation occurred through the use of multiple methods[322] that built a more synergistic understanding from the data captured through the six organisations and individuals. For example, the ethnographic approach was not a single method but rather a culmination of observations, interviews, documents, and QI methods. Furthermore, the interviews with the six individuals combined semi-structured interviews and documents. This triangulation by method helped me understand what people said, but also what they did, and what they reported. Additionally, sources such as documents provided useful background to initiatives that enabled a better conversation during the interviews, or expanded on topics which were supplementary to my study but strengthened my understanding. For example, a public participant in this study (Chris) sent me some of the reports he had co-written with other public partners about improvement initiatives for their local Clinical Commissioning Group. This provided useful insight into how the public partners worked together, and the types of areas on which they focused.

Triangulation of methods guided an iterative research process where findings were fed back to focus inquiry. The data collected from the six individuals and the five other organisational case studies was used to inform and direct the scope of the ethnographic approach taken in organisation Deep. This ethnographic approach was conducted within organisation Deep and in four of its improvement initiatives and the findings fed into the collaborative inquiry that aimed to improve PHCP co-creation. These cumulative findings also informed and advanced the direction of further investigation through the ethnographic approach. Thus, the combination of triangulation by data source and method concurrently strengthened my understanding of PHCP co-creation in practice.

I triangulated by data type[323], combining qualitative texts such as meeting minutes with audio data from monitoring meetings and quantitative measurements.

As part of the collaborative inquiry in organisation Deep, there was some triangulation by investigator[322] with two to six key individuals being part of the inquiries. While this was not extensive, it was a useful approach to check my understanding of cases against what others in Deep found. I could then use this insight to target data collection, re-check the data I had or challenge assumptions.

3.5.2 Phase 1 Sampling and Data Collection

This research for Phase 1 was conducted within organisation Deep (3.4). Deep funded and supported a specific number of improvement initiatives each year. This therefore provided me with a potential sample of improvement initiatives.

A. Retrospective Study

Sampling

Secondary data from previous Deep-supported improvement initiatives already existed. A pragmatic decision was, therefore, taken to review this data to gain insight into initiatives before collecting new data. This data provided insight into PHCP working in healthcare improvement and allowed me to test the validity and potential exploration of value co-creation. The data provided a way of testing whether value determined by costs and benefits, and co-creation (broken down by Dialogue, Access, Reflexivity and Transparency) could be investigated. This necessitated further case studies (Table 2) from within Deep where PHCP had actually worked together. Therefore, case studies where PHCP working was deemed successful were chosen. Sub-section 3.4 expands on why these initiatives were deemed separate case studies.

I discussed previous case studies with colleagues in Deep who had experienced working with the improvement initiatives. I simultaneously checked the data organisation Deep held about the various improvement initiatives. I also had ongoing contact with some of the public and HCPs from these former improvement initiatives which gave me useful understanding of their ways of working and what they achieved. A culmination of these factors led me to select Woke and Samaaj as two improvement initaitives with some level of PHCP co-creation that could provide useful insight (sub-sections 5.5.4;5.5.5).

Data collection

An extensive search through Deep's archive led me to find: over 150 pieces of secondary data including documents (funding applications, team meeting minutes etcetera); QI methods (initiatives' process maps, quantitative improvement measures, PDSA cycles etcetera); audio and video (patient stories, monitoring meeting audio etcetera); and previously conducted interviews and focus group transcripts (Table 4). These were all used as there was no reason to exclude any of the data.

This data was in audio, document, and video format. Some of the audio data had not been transcribed. I had a budget for transcription but wanted to save that for the prospective study. Therefore, I only sent off the focus groups and group discussions for (verbatim) transcription and did not get the monitoring meetings audio transcribed. The sound issues on the latter made this too costly.

Table 4 Secondary data analysed

Available to analyse	**Deep**	**Samaaj**	**Woke**
Driver Diagrams		7	1
Digital stories		1	2
Storyboard		2	1
Focus groups		1	3
Audio		1	1
Funding application documents		5	1
Interviews	4	2	10
Other	1	3	3
Patient stories		4	0
PDSAs		6	2
PI-related documents		2	11
Process mapping		0	4
Monitoring meetings			
4 month		0	3
6 month		3	0
12 month		6	2
18 month		6	3
24 month		0	9
Audio		2	3
Stakeholder mapping		0	2
Sustainability		3	1
Team meetings minutes & related documents		7	56
Team meeting agendas		0	19
Subtotal	5	61	137

B. Prospective Study

Sampling

The Phase 1 prospective study aimed to longitudinally explore the co-creation process between the public and HCPs in service change. Deep supported improvement initiatives that applied for funding from the organisation through a competitive bidding process, and had initiated a new funding call. This provided a potential of seven improvement initiatives I could work with. I read their project proposals to familiarise myself with their plans. These seven initiatives had been invited to an ‘induction day’ for new projects, thereby providing me with an opportunity to observe and engage with the teams. These insights informed my sampling:

Observations at [new] teams' induction day

Initiative AL: no patients but eager to work with them and eager to learn how
Initiative PL: - [Lead] kept saying "my project" so excluding this one
Initiative AS: no patient reps and no indication of willingness to work with them - my feeling is that it is too hierarchical (based also on prior experience of this team)
Initiative Jugat - want to co-design
Initiative IH - had a patient present. But too big and think they will need a lot of support with the improvement which may compromise my observer role when doing the ethnography - people may come and talk to me all the time
Initiative JG - team not as aware of what they are doing, therefore exclude because unsure how interesting findings will be
AL and Connect?
Initiative AL - action research at project level
Initiative Connect - action research at programme level

Fieldnotes, 4/9/15

I initially planned to work with initiative Connect and AL. Connect was one of the two initiatives with a public team member present on the day. This gave me confidence that there would be a minimum level of PHCP interactions that could help me answer the research questions. The other team with a public team member was excluded because they were a huge initiative across many sites. This could comprise the depth of data I gathered and the relationships I built. AL were eager to work with public team members and worked in a specific mental health setting which used Action Research. I felt two initiatives would provide richness of data and enable me to build relationships with the team that would facilitate a collaborative inquiry.

I shared my observations with my manager, Deep's Patient and Public Engagement and Involvement Lead. She concurred with the selection of initiative Connect. She, however, suggested initiative Jugat as the second initiative. The initiative had contacted her to ask for her support to help them to co-design with the public. I expressed I needed 'enough' data and she felt this initiative would still fit that requirement.

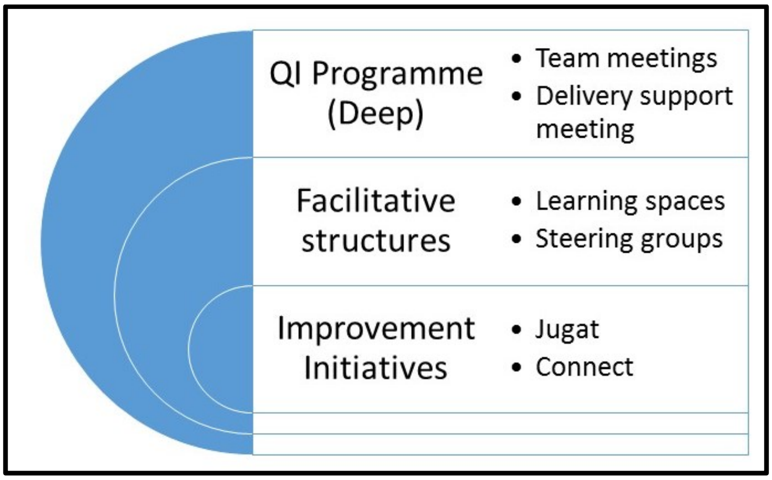
I, therefore, selected initiatives Connect and Jugat, and continued to monitor the other initiatives in case they provided more useful data.

Data Collection

The prospective study aimed to collect data at three interrelated levels to better understand how PHCP co-creation realised value for service improvement. These levels were the improvement initiatives, the QI programme (Deep), and the facilitative structures that were created to support the initiative (Figure 5).

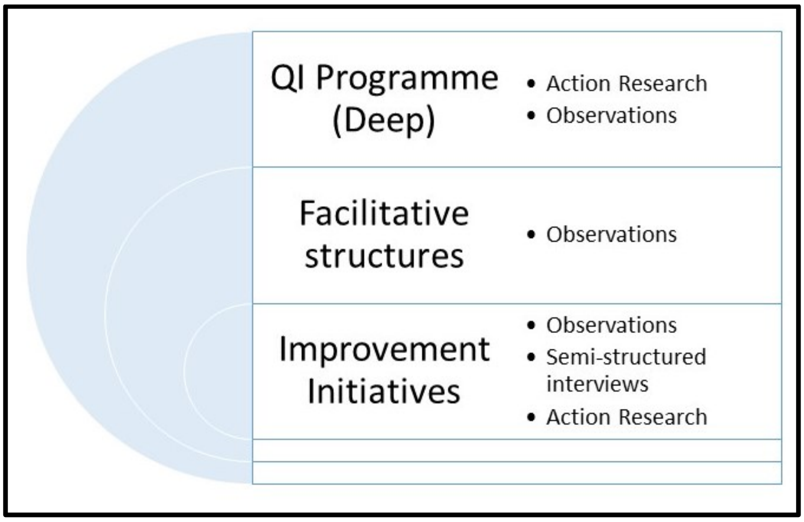
These facilitative structures were largely created by Deep, and included learning spaces and steering groups. The learning spaces varied in format but aimed to support improvement initiatives on their improvement journey. This included through sharing knowledge, and supporting and facilitating peer learning among other public and HCP co-creators on different improvement journeys.

Figure 5 Where data collection happened



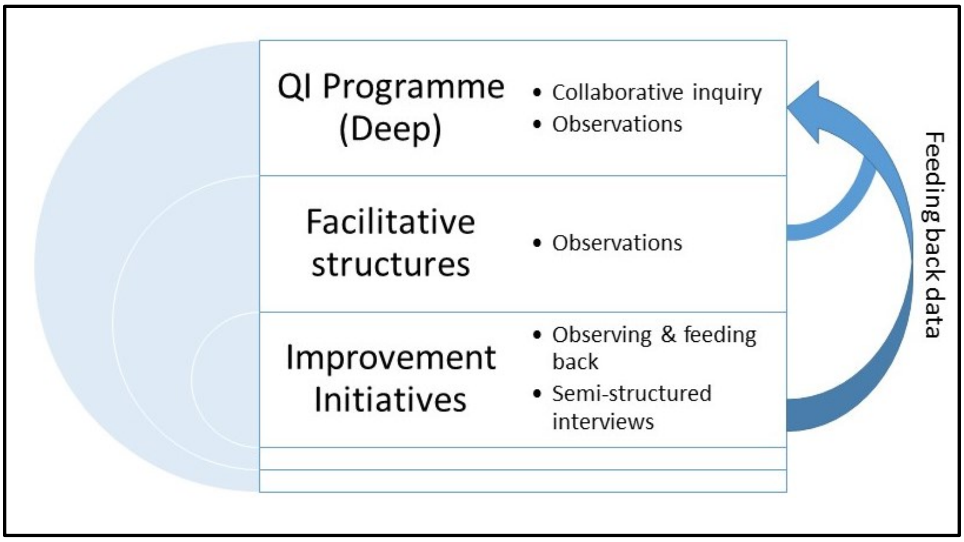
Different research methods were planned at the three levels (Figure 6). I planned to collect ethnographic data at the improvement initiative level, but Jugat were keen to make co-creation work and were receptive to Action Research. The busyness of the facilitative structures meant ethnographic observations were the natural choice at this level. My position as a potential ‘insider’ in organisation Deep made me consider conducting more participatory research at this level. This aimed to improve how the public and HCPs worked together in the improvement initiatives. Multiple methods were, therefore, considered useful to answer the research question, rather than because they aligned with a specific paradigm[324].

Figure 6 Planned methods of data collection



The actual data collection methods slightly but significantly changed (Figure 7). Action Research did not happen at the improvement initiative level. This was largely because initiative Jugat struggled to initiate the planned improvements (5.5.7). There was limited collaborative activity and other priorities took precedence for the initiative's team. Observational data was collected and fed back to the initiatives and programme.

Figure 7 Actual methods of data collection at various levels



The challenge of participatory approaches in practice

Multiple attempts to initiate structured Action Research failed at the programme level and the method was therefore adapted to a broader collaborative inquiry. QI facilitators in Deep were already under workload pressure and did not have the time needed for participatory approaches[325]. This echoes Mathieson's (2017) experience when using Action Research to implement a booklet with community nurses[326]. My reflections highlight some of the difficulties in initiating this method of inquiry:

Action Research set reflections:

Needed a natural trigger. [Action Research] wasn't a priority for [QI facilitators at Deep], but then at the last [Collaborative Learning] Network (last week), BOTH Bethan and Diedre went and Bethan experienced action learning for the first time. Bethan, in the team meeting, stated 'perhaps we need to have something like that to support us, particularly the confidential space where whatever is said, does not leave the room".

But I had mentioned action learning before and started to try and get dates with them, and this hadn't happened. Therefore, does experience of action learning need to come first, before the suggestion and implementation of it? My previous attempt to start action learning was post Diedre's first [Collaborative Learning] Network session, so that may be why she was more amenable to it.

Fieldnotes, June 2016

I continued a collaborative inquiry at the programme level by initiating reflective meetings with Deep colleagues. Additionally, I would share reflections and observations to initiate discussions and reflection on changes that could be made to enhance collaborative working, and increase the likelihood of improving healthcare (Figure 7). Despite my effort to continue collaborative inquiry and get directly involved, this research was not as participatory as I had envisaged:

Reflections about participatory approach being taken

I'm struggling to place this research on the participatory paradigm – where does it fit? At the beginning, both teams were really interested and engaged in ensuring healthcare professionals and patients/public worked together, and I explained my research was to help them make that work. I now question whether their enthusiasm was for other reasons. I feel that enthusiasm has waned along the way (or was perhaps never there, but was stated due to my perceived role as a member of the organisation [Deep] that had given them funding and was going to support them for 18 months!). So I'm now unsure where the research approaches sit. 18 months is perhaps a long time for a participatory project, when the sub-process being improved is not in the mind's eye of the project team. The improvement has taken over in focus and perhaps always was the focus. So it is difficult to embed more comfortable participatory approaches to the research when this is the case. I fight the shift into a more traditional ethnography, as that won't shift what is happening in these projects, but I'm currently struggling to see how to embed more participatory approaches. With Connect, I was thinking of bringing the partnership synergy aspect to the table – feeding this back to them and questioning them, on whether they believe they are so synergistic that they aren't looking towards patients/public. With Jugat, this is difficult as there really isn't a level of collaborative practice and I don't feel as embedded in the team – I feel like more of a traditional ethnographer with this team. Essentially, I think the conclusion is that embedding participatory approaches, which have the potential to change/influence things is hard when you are improving a sub-process [co-creation]. The sub-process needs to be made more overt for participatory approaches to have a real affect. I feel lost, drowning between a desire to make change happen, and the reality of what appears to be happening.

All very depressing really.

Fieldnotes, 14/10/2016

Ethnographic approach

This thesis took an ethnographic approach combining participant and non-participant observations, document analysis, and semi-structured interviews in initiatives Jugat and Connect and organisation Deep. The data was collected over 14 months (October 2015-December 2016) with follow up visits to the initiatives to share findings after this time.

The power of being able to observe practice had become apparent by the time I had started this PhD. Research highlighted the potential of video recordings of healthcare practice, or patients stories and accounts, as a reflexive method to improve healthcare safety[327]. This led me to consider an adapted ethnographic approach where I observed and fed back findings to provide useful reflections to the public, HCPs and QI staff I was researching with. Confirmation from Rick Iedema that this was important made me commit to this way of working: "I agree with you that ongoing feedback of data to participants in improvement projects is critical, so they gain ownership over issues, challenges and solutions" (Personal e mail, 10/9/2015).

Ethnographic Observations

My ethnographic observations gathered data from initiatives Jugat, Connect and organisation Deep. I observed Jugat and Connect's regular improvement initiative meetings, and related meetings and events in healthcare and non-healthcare settings. I also observed organisation Deep's collaborative learning events and internal meetings where the initiatives were discussed (full log of observations in Appendix B).

My observations were documented in an A6 size notebook. I'd seen somebody use a laptop for fieldnotes in a setting with many public partners. Some of the partners were audibly perturbed by the constant tapping and felt they were being spied upon. This, therefore, encouraged me to use a less obtrusive method to capture my fieldnotes. I used Spradley's framework to shape my observation plan for the first time I entered the field (Appendix E). I drew analytical diagrams and coded my fieldnotes while in the field. I scanned the notes to provide a backup and only typed them up when I was ready to analyse them.

Verbal consent was attained from everybody who was part of the ethnographic observations. This was sought regularly during the beginning when I first entered the field. I would remind people what I was doing and what the data would be used for. As I continued observations, I would get verbal consent when new people joined. A pharma employee joined initiative Connect some months before the initiative was due to stop. He had previously mentioned the difficulty of getting consent because of his company's regulations. He was therefore excluded since he was not critical to my line of inquiry.

I wanted the data I collected to be useful to both the improvement initiatives and organisation Deep in a way that aligns with the pragmatist paradigm[328]. Specifically, I felt feeding this data back could enable reflection and initiate change, while knowing I would never feedback data that could be attributed to an individual or was shared in confidence. However, this was difficult at the initiative level. I had to frequently reflect on what I should share especially at the beginning when my relationship with the team was still forming. I reflected with my colleagues, that in the worst case scenario, the initiative could withdraw consent if I fed back something they did not like:

Reflections about feeding back data

When do I feedback data, and what, and what do I keep to myself? How do I achieve the balance of feeding back something, therefore, appearing/feeling useful to the team while maintaining research integrity, and not losing the trust of the team by revealing too much about the dynamics of the team, which may offend.

Q: What is the optimal distance for observation for improvement?

With initiative Connect, can this balance be achieved by capturing the narratives of the GPs' learning & not all the ones about team dynamics.

Feeding back too soon in a QI environment led to Noreen acting quickly – need to figure out how this effects trust as could come across as a spy.

Fieldnotes 4/12/2015

I fed back (anonymous) observational data about the improvement process in practice and tensions that may have arisen. For example, I highlighted to Connect that I'd observed some primary care teams commenting that they were doing extra work without financial compensation. Initially the team were quite frosty and the clinical lead responded "well there is no money" (Nima, HCP). However, as time went on, they looked for ways to incentivise the primary care teams. Alongside this, I queried the teams' plans to work with public partners.

The majority of the ethnographic data I fed back was to individuals in organisation Deep. This data was all anonymised and were general findings rather than issues that could point out specific individuals. This data gave individuals at organisation Deep a fuller understanding of the improvement initiatives, and enabled us all to try different strategies to encourage better PHCP working. For example, feeding back reflections and observations just before a monitoring meeting with Connect enabled Deep team members ask strategic questions to uncover and prompt planning about their future plans of PHCP working (Fieldnotes, 12/12/2016).

Semi-structured interviews

The semi-structured interviews in Phase 1 aimed to provide greater insight into participants' perspectives of the improvement initiatives and learn about their plans. These were carried out with members of Jugat (5) and Connect (5) and organisation Deep (7). Interviews with individuals from initiatives Jugat and Connect were largely conducted face-to-face, with three from Jugat conducted via phone or skype. Three interviews with individuals from organisation Deep were conducted face-to-face, and four were carried out over the phone or on skype. One of the interviews carried out over the phone was excluded due to sound issues. An interview guide was used (Appendix C) and I probed during the interviews to ensure I understood what the interviewee said, or to garner more information.

Three main issues arose with these interviews. Firstly, two individuals from initiatives Jugat and Connect did not respond to the requests to be interviewed. These individuals seemed more sceptical of PHCP working and, therefore, would have provided interesting and useful insights. Secondly, there was a sense from Connect in particular that nothing sensitive or controversial would be said in these interviews: "It's fine, I'm not going to say anything that perjures myself, don't worry" (Nima, HCP). This was reinforced among those who had more junior roles. For example, the nurse and the newly recruited community nurse in Connect both appeared to hold back detail because of what they thought senior people or the organisation may say: "But the primary care work was the heavy side of the project which is, we did, I would say, I shouldn't say it, Dr Nima wouldn't be pleased" (Sarah, HCP). This was despite me reminding them that everything they said was anonymous and I would not feedback those details.

Thirdly, I was part of organisation Deep and was interviewing colleagues which had the potential of influencing their responses, especially as I was part of the PI team. This however, did not appear to be an issue since the interviewees saw themselves as part of a collaborative inquiry into PHCP working in the improvement initiatives rather than organisation Deep. This encouraged the Deep team to be open about what they felt. In one situation I did feel the interviewee was being overly positive about PHCP working and I therefore challenged him:

> **Interviewer: "…it came across clearly, I just felt, again it could have been just me being oversensitive as well… I am wondering how much people say to me about PI which they feel they *need* to say, rather than… really feel…**

> **Nii Kpani**: "I suppose the perspective I would come back to you with is that, having been involved with Deep for five years I know what we are trying to achieve for the most part with PI and I know what a low level and a higher level of that achievement looks like to some degree, and so I, from my perspective, I'm attempting to compare what I've seen with what we're trying to achieve whilst taking into account that what I'm seeing might not actually be the full story."

Documentary data

Relevant documentary data for both initiatives and organisation Deep was collected. This included the process maps, completed sustainability planning tools, reports written or about the initiatives, agendas and reports related to events that took place, and meeting minutes.

3.5.3 Phase 2 Sampling and Data Collection

A. Sampling

Phase 2 aimed to test the findings from Phase 1 in other healthcare improvement contexts and this informed the sampling strategy. Some sampling was purposive to gather data from organisations similar to Deep (Table 5). Colleagues at Deep shared my research call (Appendix G) with individuals at organisations Stanter and Tayjan. I aimed to increase data from organisations that use QI methods to answer research question 1c. Another colleague heard presentations from organisation Jinja at a conference and were aware they use these methods. He, therefore, put me in touch with two individuals he had met. Participants from Jinja, Stanter and Tayjan connected me to others in their organisation. This led to four extra interviews in Stanter and one extra in Jinja, and some prospective participants who did not respond. Additionally, two other UK-based healthcare improvement organisations whose work I was familiar with, did not respond.

Continued overleaf.

Table 5 Organisations answering the call

Organisation	**Primary Focus**	**Location**	**Data source**	**How sampled?**	**Interviews that didn't happen**
Ekta	Healthcare improvement	UK - specific geographic location	5 Interviews, Documents	Answered call	1
Jinja	International development	International	3 Interviews	Purposive	2
Monitor	Healthcare improvement	UK-wide	2 Interviews, Documents	Answered call	1
Stanter	Healthcare improvement	UK - specific geographic location	5 Interviews	Purposive	Unknown
Tayjan	Acute care	USA	1 Interview, Documents	Purposive	2

I did not want to pre-empt and thereby, restrict the experiences that I may gather. Phase 1 data highlighted variation in how people defined healthcare improvement and QI. I, therefore, wanted people to share experiences of improvements they may feel were relevant, rather than solely target specific organisations. Thus, I disseminated a call for people who were interested in sharing their experiences to contact me. This call was primarily shared via e mail, including to contacts in neighbouring or similar organisations, and through the CHAIN network. Some of the organisations put the call in their newsletters. The call specifically excluded Experience-Based Co-Design because of a big evaluation of this method that was taking place at the same time. Seven individuals answered the call and shared their experiences (Table 6). All individuals were asked to share the call with others, therefore enabling snowball sampling, as I aimed to gather multiple perspectives from the same initiatives. However, this did not happen in these 7 cases and interviews had already been conducted. I decided to keep this data in this PhD because the data had been collected, and provided relevant and interesting insight.

Table 6 Individuals answering the call

Name	Main perspective
Ajeet	HCP
Amanda	HCP
Chris	Public
Dolores	HCP
Isabella	Public
Nana	HCP
Rohinton	Public

I was unable to directly contact people before sending them the study information guide (Appendix H) because of ethics restrictions. This was specifically the case for public participants. Two of the participants who gave their phone number in the first e mail they sent to me were people who then stopped responding to my subsequent e mails. I stopped contacting all potential participants if they did not respond after three repeat e mails. One prospective participant was frequently in hospital. Two separate dates had been arranged for an interview with them. The first date came and went because they had not provided a preferred time for me to contact them. I e mailed them to ask if they wanted to still share their experiences and they stated they did. However, when I e-mailed them to confirm near the suggested date, I received no response. I therefore stopped contacting them.

B. Data Collection

The 23 semi-structured interviews for Phase 2 aimed to test findings emerging from Phase 1. These interviews largely took place via Skype or over the phone. One took place face-to-face.

Everybody who agreed to be interviewed was provided with an information sheet about the research in the wider programme of which this PhD was a part. They were asked to complete a written consent form (Appendix I) prior to the interview, as in the Phase 1 semi-structured interview data collection. I would ask permission before audio recording the interviews and these were transcribed verbatim. At the beginning of the interviews, I would go through the consent form with the interviewee. I would remind them of the anonymous nature of the interviews and that they could stop the interview at any time. I made pre and post interview reflections for the majority of the interviews.

An interview guide framed these questions (Appendix D) and I probed to ensure I understood what interviewees said, or to garner more information.

I stopped collecting data when I had reached saturation and the interviews were no longer presenting new findings.

C. What constituted a case study?

Phase 2 aimed to collect data from comparative case studies of similar but different organisational settings that could test the findings emerging from organisation Deep in Phase 1.

The lack of a definition quantifiably explaining the amount of data needed for a case study led some to challenge what I deemed a case. These challenge came particularly from colleagues who were more familiar with quantitative methods. They challenged whether Tayjan could be deemed a case due to only one interview occurring. I reflected on this with other colleagues who were using case study method. I determined, using Stake's (1995) definition of cases as "bounded" or "integrated systems"[319(p2)], that Tayjan was a case. Grace (HCP) was in a senior leadership position in Tayjan and provided experiences of PHCP working across the organisation. These were not just her personal experiences, but also those of colleagues. Additionally, I gathered published articles about the organisation, and data from Tayjan's website to strengthen the information Grace provided.

These criteria of cases as "bounded" or "integrated systems"[319(p2)] excluded the seven individuals (Table 6) from being organisational case studies. Many of these individuals described personal journeys scattered over different contexts. It was difficult to 'bound' them at a level which was comparable with the other case studies. Namely, they did not enable the depth of understanding of PHCP co-creation in one organisation. Chris's (Public) description of experiences in one Clinical Commissioning Group (CCG) challenged this. After reflection, he was excluded from being a case study because his perspective came from a public partner working outside of, rather than within, the organisation. He did not provide the level of detail about the organisational working that Grace (HCP) was able to provide from being a senior leader inside organisation Tayjan.

3.6 Reflections on my Position as a Researcher

As stated in Section 3.1, this study was influenced by postcolonial, decolonial, and feminist thought which positions researchers, and their experiences, as intrinsic parts of the research process[286,287]. This influenced my position as a researcher throughout the process.

I had different positions throughout the data collection switching between 'insider' and 'outsider'[308] . In Phase 2, I was very much an outsider looking in. In Phase 1, my position varied. I regularly reflected on this throughout my data collection, including on how it influenced my research process, and added these reflections to my fieldnotes to check.

I was employed by organisation Deep. I would present and run sessions at various Deep learning spaces, more so in the beginning of my research and towards the end of my data collection. I, therefore, had a visible profile. I was also part of the two person PI team and this was an area in which many improvement initiatives needed support. We were seen as facilitators of this which strengthened rather than detracted from the collaborative inquiry. This profile made it easier for me to access initiatives and the sites where they were located. It led to other teams that I had excluded from the sampling asking me for support. This enabled me to keep abreast of the PHCP activities in the other initaitives, and learn more about the relationship between improvement initiatives and the wider context, which strengthened my findings (4).

My position in Deep led to me being towards the "inside learner" side of the "outside expert"-"inside learner"[293] spectrum throughout this research. I was part of internal meetings which gave me an opportunity to initiate and contribute to collaborative inquiry. This inquiry specifically focused on monitoring and optimising what the initiatives could achieve, but also focused on how the public and HCPs worked together. This could lead to improvement initiatives seeing me as somebody from Deep with an interest in supporting the improvement process. My position did not appear to challenge my relationship with the initiative teams since there were always Deep team members who facilitated the QI process and liaised between Deep and the initiative. However, I was aware I may be seen as a 'spy' for the organisation, although there was no evidence to support that this occurred.

The number and quality of interactions I had with the improvement initiatives influenced whether I was seen as, or felt like, an outsider or an insider. I initially thought I would be more of an insider in initiative Jugat. However, the lack of regular meetings and their disengagement from Deep learning spaces did not enable me to build a collaborative relationship. Therefore, our relationship was always more formal. I would dress smartly when I met with them, and there tended to be a physical and social distance between me and the team. At times, I felt like a true outsider and even questioned whether I was doing non-participant observation:

Reflections:

I still feel that I am more of an OUTSIDER, and that although this enables me to critique the team/processes etcetera it could be why the team don't see [any] value in my work and don't engage; e.g. Mandeep has rescheduled his interview twice

Fieldnotes 8/9/2016

Initiative Connect, however, would meet weekly which enabled me to rapidly build relationships with them. Crucially, I was able to share informal interactions with them. For example, I occasionally shared pre-meeting coffees with some team members or took the same taxi with them to specific meetings. These informal interactions helped me learn more about the team members and their personal lives.

Additionally, I felt my position was influenced by similarities and differences in mine and the team members' characteristics. I am a brown-skinned, female, raising Punjabi-speaking children. My parents were born and raised in East Africa. These factors enabled me to relate with initiative Connect. The clinical lead from Connect was a mother of two children and had Pakistani-born parents. She understood Punjabi so I would use the language for terms that I could not readily translate into English. Eventually, two more brown-skinned females would join, one with a child who I also connected with on a personal level. I was expecting a baby during my data collection phase and my reflections of a post-baby visit highlighted potential challenges of this insider status:

On the 24th, Noreen and I visited the Connect team with the babies. An indication of how much of an insider we both are. Nima mentioned "and here are our new team members" [referring to the babies] as we opened the door. Being thought of as such insiders has really helped us understand what is going on, but it also potentially hinders the extent to which we challenge - Because challenging risks our insider status. This is perhaps where a more formal action research approach could have helped, but again,

> the question is, how do you implement that when [working with the public] is a sub-process that we want to improve, rather than the improvement itself?
>
> **Fieldnotes 24/3/2017**

A Jugat team member was also a mother and we would empathise with each other over childcare issues. However, the closeness I had with Connect did not materialise with Jugat. The question remains, are good relationships a precursor to collaborative inquiry, or does collaborative inquiry enable better relationships?

3.6.1 The influence of the positivist paradigm

The positivist paradigm has "always dominated in science and medicine"[123] and did affect this research. Even though this paradigm did not frame my own approach it influenced the context of this research. This included the structures which guided and examined the quality of this research and the settings in which it was carried out. For example, my final internal PhD review process was structured for quantitative students, and reporting guidelines limited my written submission to four pages. I had to bullet point qualitative findings and could only really expand on these in the presentation.

This research was conducted in healthcare organisations and academic institutions where the positivist paradigm was influential. This paradigm promotes a single, objective truth[296,329] gathered through measurable, largely quantifiable data[294]. The researchers are independent and distant from the inquiry[294] and do not influence the process or outcomes. There is a preference for specific methods and a hierarchy of inquiry that sees randomised control trials as the strongest form of research[121,330]. In response, I continued to say I was conducting a mixed methods study at the beginning of my PhD. I planned to provide the measurable element that could ease the nerves of those I was surrounded by who felt I would otherwise produce biased, non-generalisable results. It was only when my supervisor who had completed a qualitative PhD said it was ok to do a qualitative study, that I started to own this line of inquiry.

The surrounding positivist, medicine-focused environment led to me frequently reflect on the amount of data I collected. I was frequently asked how much data I would collect by quantitative experts. I realised the 'right' (expected) answer for interviews was "over 20 interviews" not "until I had reached saturation". Together with the relatively junior position that the Early Career Researcher title bestows, these questions made me frequently reflect on whether I was collecting *enough* data. It led to me being less concerned about voices that I may not be hearing and limited my investigation of ‘ordinary activities’ in their ‘natural habitat’[304]. Situations that would enable me to answer the research question were prioritised over, for example, observing the mundane but necessary daily work of HCPs.

Green (2019) warns about the challenge of initiating power sharing in this paradigm because "…"experiential knowledge" is by its very nature based on individual perception and observation and thus easily characterized as at best "sui generis" and at worst "anecdotal.""[91] This view was relevant to both the research process and the focus of this inquiry. In the drive to promote the practice of evidence-based healthcare[331] ‘evidence’ can prioritise clinical expertise over patients’ involvement in their own care [332–335]. Some HCPs I met were still unconvinced that public partners should influence healthcare planning and delivery. This influenced how specific HCPs viewed my research and the value they felt it had. I was after all, exploring something that was "all just motherhood and apple pie" (senior clinical lead about PI, relayed through informal conversations with PI Lead).

3.7 Theoretical Framework

I aimed to apply middle-range[336] theories created from empirical data which seek to describe and explain specific phenomena[336]. These theories are "close enough to observed data to be incorporated in propositions that permit empirical testing"[337]. Middle-range theory can provide useful explanations of practice and for research[126].

Lasker et al.’s (2001) partnership synergy was originally tested as the theoretical framework for this thesis[338]. This theory explains the factors that are necessary for synergistic partnerships and, therefore, fit with my inquiry into how PHCP partnerships could be optimised. The theory itself seemed to have been created with rigour and there was an online tool[4] that could help people assess how synergistic their partnerships were. I, therefore, felt this could provide a useful tool to help improvement initiatives reflect on their PHCP partnerships. However, it was difficult to get the teams to fill out yet another tool which did not fit into their priorities of improving healthcare. Additionally, coding data against partnership synergy was laborious, especially as my other deductive coding frameworks encompassed some of its elements. Thus, a different framework was sought.

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[4] Has since become unavailable

Value co-creation (VCC) offered a useful, alternative theoretical framework. VCC conceptualises a shift from businesses creating value for customers, to "…the *value-creating system*…within which different economic actors – suppliers, business partners, allies, customers – work together to *coproduce* value."[225(p66)] The ethos of coproducing value through a constellation of collaborative partners[225] echoes the desires and drive to establish PHCP partnerships including in service change[9] as described in chapter 2.2. Additionally, VCC has been positioned as a potential theory to establish better partnership working in healthcare[34,76]. Janamian et al. (2016) highlight its potential to support the public to shape healthcare systems[34,271], yet there remains scant literature exploring VCC's application to shape or assess PHCP partnerships.

Specific components of Ramaswamy et al.'s VCC increase its potential as a theoretical framework. This includes the framework being positioned as the "enactment of creation through interactions"[88] and its Dialogue, Access, Reflexivity and Transparency (DART) sub-component[82,86]. As described in chapter 2.4.3, positioning VCC as an interactional approach means it has the ability to transcend, rather than be limited to, any specific context. Similarly, the focus on co-creation as "enactment of creation through interactions"[88] could theoretically encompass a range of PHCP working. This could include PI where members of the public are invited to be part of healthcare improvements initiated and led by HCPs. But the term co-creation could also include coproduction where the public and HCPs have equal power to initiate and shape improvements. Additionally, the theory states the DART sub-components are the "building blocks" for quality interactions[82,86]. This potentially provides both a useful way to explain how to create high-quality PHCP interactions for service change, and an analytical framework. Thus, VCC could be a useful theoretical framework bringing potential to transform PHCP working through improving what is realised through the co-creation process and the co-creation experience[85,89].

3.8 Data analysis

This sub-section describes the analysis process that I carried out of secondary and prospective data, and how these data were then combined to provide answers to the research questions.

The researcher does not analyse data in a vacuum but rather constructs its meaning from what they know, and based on their own experiences[309,339]. Findings do not then naturally emerge, but are constructed:

> "Understanding the 'meaning' of data properly involves a broader perspective on history, social structures and comparative cases as well as in-depth grasp of the particularities of the data set in question."[309]

My journey formed an iterative process of data collection, analysis, results informing further data collection, and re-analysis in line with sequential analysis[323]. I realised during data collection and preliminary analysis that I could construct theory from the data. Therefore, my analysis was influenced by constant comparative method[340,341]. This is "designed to aid the analyst who possesses these abilities in generating a theory that is integrated, consistent, plausible, close to the data"[341(p103)]. This method was adapted to use alongside deductive coding frameworks.

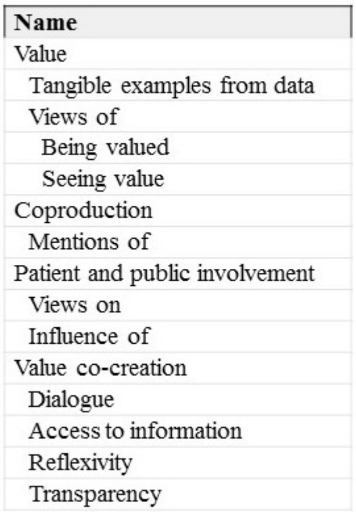
Data analysis was influenced by Fereday and Muir-Cochrane's (2006) hybrid approach to provide theory-based *and* data-driven analysis[342]. The hybrid approach combines deductive and inductive coding to build understanding through a priori constructed knowledge and a posteriori coding grounded in empirical data and human action[342]. This approach aligns with the interrelated, cyclical nature of theory and theorising[293] that guided this research. Glaser and Strauss remind us that "the generation of theory coupled with the notion of theory as process, requires that… [data collection, coding, and analysis] should blur and intertwine continually"[341(p43)]. This concurrent data collection, coding, and analysis enabled the construction of themes through iterative deductive and inductive approaches that evolved between the secondary and the prospective data analysis in this study.

3.8.1 Secondary (retrospective Phase 1) data analysis

I started by analysing the secondary data. I gathered the significant amount of data on initiatives Woke and Samaaj and entered it into a qualitative data analysis software (NVivo 10). I used the data analysis software as a way of collating all the data and providing some order. I familiarised myself with the data for Woke first and then Samaaj. I read the initiative proposals where they stated their intentions, followed by interview and focus group transcripts. I listened to the audio from the progress monitoring meetings.

The aim of this analysis was to get rich description from within the case of what happened in practice, and explain why this may have been so[343]. I created a framework for deductive coding that was informed by my research questions (Figure 8). I wanted to test the feasibility of coding against concepts such as value co-creation and value, especially as the former (using DART) had not been used in healthcare. Certain codes, such as coproduction and value were kept vague to build their definitions from the data. I tested the deductive framework using a sample of the data. I did not want to assume the key findings and, therefore, this led me to iteratively and simultaneously deductively and inductively code.

Figure 8 Deductive coding framework



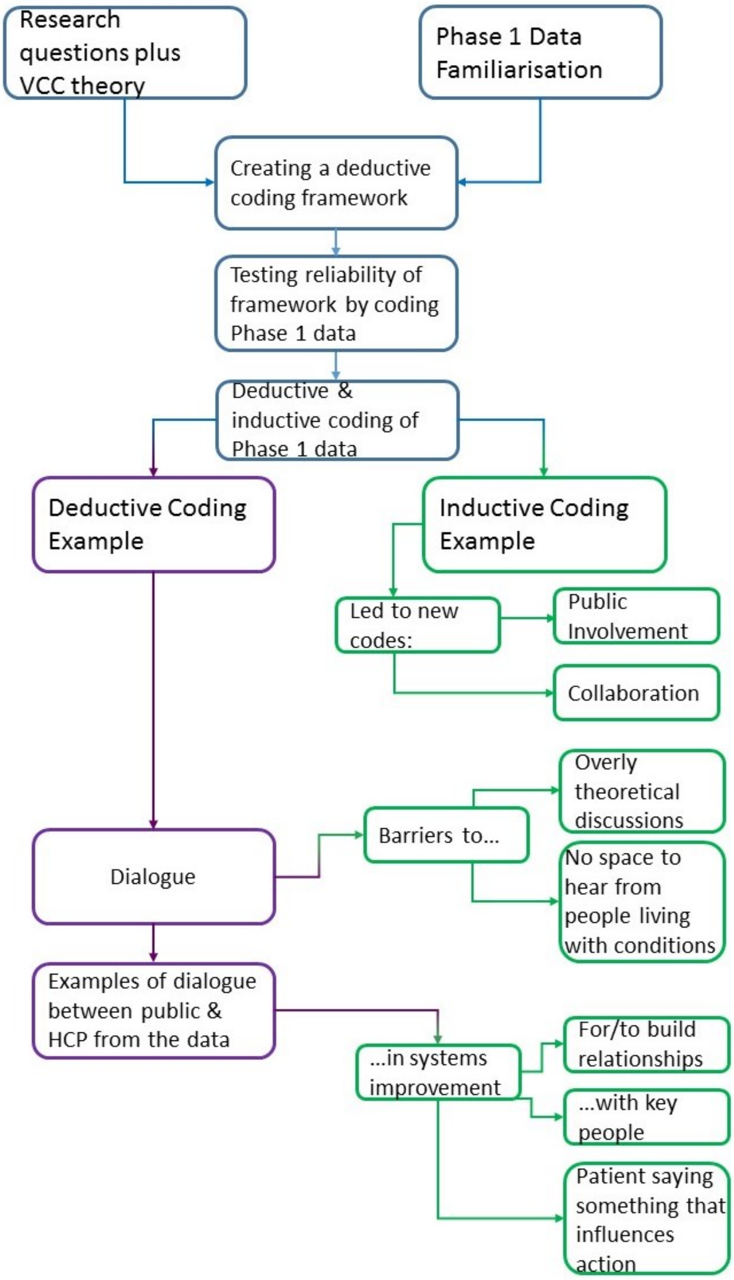
Name

- Value
  - Tangible examples from data
  - Views of
    - Being valued
    - Seeing value
- Coproduction
  - Mentions of
- Patient and public involvement
  - Views on
  - Influence of
- Value co-creation
  - Dialogue
  - Access to information
  - Reflexivity
  - Transparency

I coded the rest of the data, expanding the coding framework based on the inductive findings. I compared and contrasted what was said or happened within data sources for each case, for example, looking for consistency or contradiction within the interviews. I then did this across data methods, for example, comparing what was said in the interviews to discussions at monitoring meetings.

The combination of inductive and deductive coding enabled more complete understandings of the data and provided richer answers to the research questions. The deductive coding framework was particularly important in secondary data analysis (retrospective Phase 1) to test application of potential theories, and expand understanding of concepts such as ‘Value’. At the time of analysis, neither Ramaswamy and colleagues’ value co-creation[82,86,109], nor Lasker et al.’s partnership synergy[338] had been explored in any real depth for PHCP partnerships for service improvement. Therefore, the coding focused on highlighting examples of VCC like ‘Dialogue’, ‘Access’ etcetera in the empirical data. It also tested the potential of ‘partnership synergy’ by providing initial insight of what these concepts could mean in the context surrounding this research. The concurrent inductive coding enabled new codes to be constructed for significant concepts present in the data that were not accounted for in the deductive framework. Additionally, the inductive coding brought depth of understanding to the deductive framework by demonstrating examples from Phase 1 data or helping construct sub-codes that provided a deeper understanding. Figure 9 shows a simplified example of the interplay between deductive and inductive coding in the secondary (retrospective Phase 1) data analysis.

Figure 9 Secondary (retrospective Phase 1) Data Analysis Process



I grouped codes to construct key themes that related to my research questions. For example, these codes described or explained the nature of PHCP interactions, and QI processes that the initiative may have used. I then paused this analysis. This was a pragmatic decision because of how wide the inductive coding had become, and because I could not yet say which themes were going to be important when I brought in the rest of the data.

3.8.2 Prospective data (Phase 1 & Phase 2) analysis

As I prepared to set up my prospective Phase 1 study on NVivo 10, I realised the codes from the retrospective could not be merged with a new file. This meant I would have to open the retrospective data file and manually check the codes and data each time I needed to look at them. I decided this would not be practical to do across three separate files (one for each of the studies). Therefore, I used one NVivo 10 file to store both Phase 1 prospective and Phase 2 data. I coded data from both studies in the same place which aided my sequential analysis. I added data from both phases as I collected it.

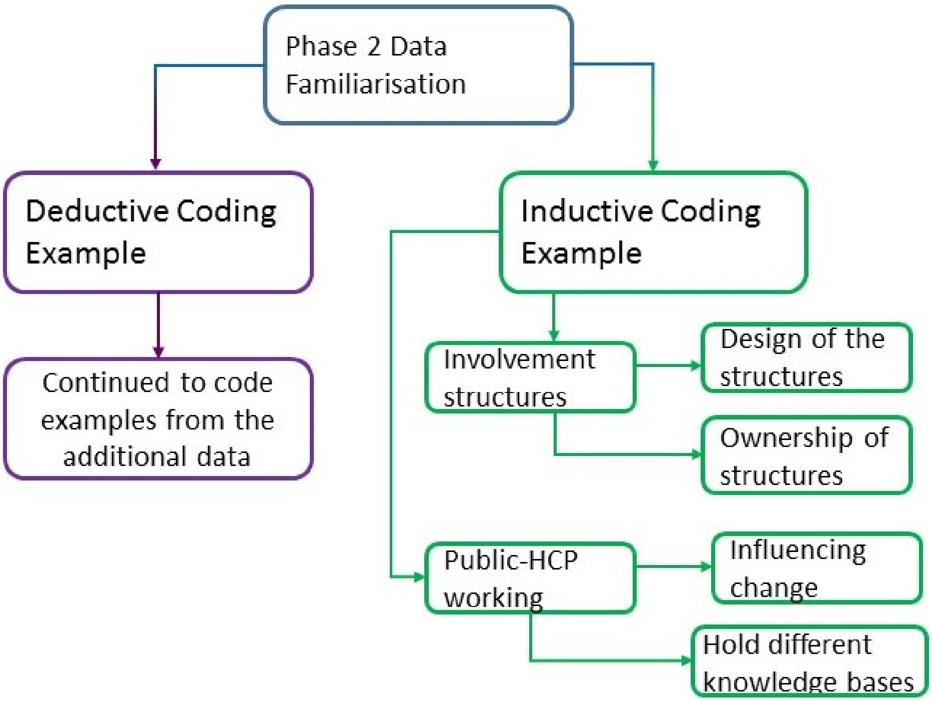
I started to code my fieldnotes during the middle to later stages of my fieldwork. I had by then a strong sense of my research questions and the data that could sit under them. Therefore, I highlighted quite broad codes such as 'hierarchies' on my fieldnotes. Reflection and coding like this proved particularly useful as it helped steer data collection during Phase 2 and subsequent analysis.

I familiarised myself with the data from the Phase 1 prospective study and the Phase 2 study by reading and re-reading interviews, reflections, observations, and then going over the rest of the data. Together with the codes from the observations, the research questions and the theoretical frameworks this helped me create a framework for deductive coding (Appendix J). I conducted simultaneous iterative deductive and inductive coding on some observations from initiative Connect and five interviews from Phase 2 to test the framework. I then continued coding all data from initiatives Connect, Jugat, and the Phase 2 data. I wrote reflections as I coded that I would add to during the iterative move between coding and referring back to the data.

I compared data from within the same source. For example, I compared the beginning of an interview with one participant where they stated they felt fine about being unpaid to the end of the same document that showed their frustrations about non-payment. I compared interviews to observations to explore what people said, to how they acted or what they would say informally. I aimed to "assure[…] that all data are systematically compared to all other data in the data set"[344].

This interplay between deductive and inductive coding continued in the prospective data analysis. The deductive framework provided a way to connect, compare, and contrast the data from multiple cases, individuals, contexts, and temporalities. The framework, therefore, provided a useful thread that brought together the secondary (retrospective Phase 1) findings and the prospective data analysis to provide a more cohesive understanding of the constructs being explored. Figure 10 shows an example of the importance of inductive coding in the prospective data analysis as it uncovered a range of significant constructs that influenced PHCP co-creation but were not in the deductive coding framework. The prospective data analysis then provided rich understanding of key previously unaccounted for constructs from multiple contexts, people and times.

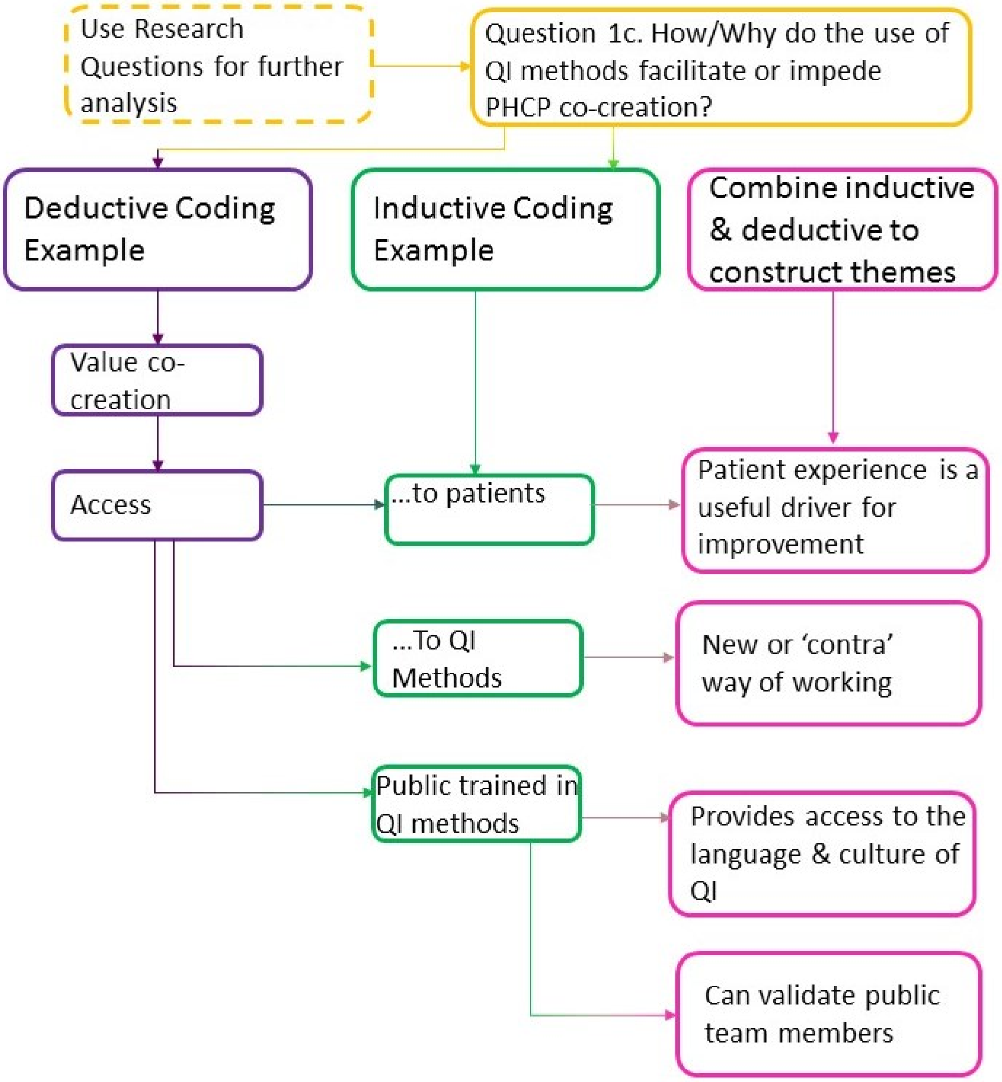
Figure 10 Prospective Data (Phase 1 & 2) Analysis Process



3.8.3 Combining all data to answer the research questions

The interplay between deductive and inductive coding was crucial to the construction of themes that provided answers to the research questions. The deductive and inductive coding from the secondary data and the prospective data analysis were combined. The research questions then provided pragmatic focus for further analysis and guided the construction of themes that provided answers. A simplified version of this process can be seen in Figure 11. Crucially, the combination of deductive and inductive codes from all data sets built a more comprehensive and synergistic understanding that balanced a priori assumptions and theory with empirical data.

Figure 11 Combined Retrospective & Prospective Data Analysis Process



To explain this in more depth, as the codes began to swarm, I started to group them into themes. I looked at the themes that were being constructed for both the retrospective and prospective studies. I continued to reflect on my research questions and reassessed the data. I realised there were interesting and relevant themes that could answer the research questions and address gaps in the literature. I, therefore, focused on these specific themes (value of co-creation; use of QI methods; participant and case descriptions; spaces; power etcetera.). I then grouped and regrouped the codes by themes, noting relevant codes from Phase 1 retrospective data. I iteratively moved between the codes, the raw data, and back to the specific themes. I did this until I had reached theoretical saturation and nothing new was forthcoming[341]. I compared the sources for the themes to assess whether they came from a single or multiple cases and whether there were comparable or unique features. As I wrote the chapters, I would go back to the raw data to confirm findings.

Throughout this process I shared main themes and constructed theories with my line manager who had knowledge of the empirical context. I did this in lieu of a second coder, and to provide a method of reflection on the theories that were constructed.

3.8.4 Validation

Initiating and being part of a collaborative inquiry provided regular ways and opportunities to reflect on and adapt methods, and validate findings. The focus of this validation was to critique and challenge my findings as I was concerned that many people felt these resonated with their own experiences or data. However, I did not find anyone who substantially disagreed with what I had discovered. Conversely, presenting these findings to diverse audiences comprised of the public, HCPs, researchers, QI or PI practitioners and so forth, highlighted concurrence in a wide spectrum of environments.

I would share findings throughout the research process with members of the wider service user research/PI/public partner communities. This was important to ensure the findings remained valid and also relevant. Early interactions with a Sociologist-patient advisor confirmed the direction of findings. Specifically, she highlighted the exploration of value could be useful for her own involvement in shaping healthcare systems. The findings resonated with individuals in national PI networks from very different contexts but funded by the National Institute of Health Research. This included an organisation with the same remit as Deep. However, that organisation was more research-focused rather than healthcare improvement-focused. I met somebody who had carried out research in a Biomedical Research Centre and we were surprised by the similarities in our findings. Additionally, I shared findings with over 120 public partner, HCP, researcher attendees at Deep’s regular learning spaces.

I offered to share findings with the two prospective (Phase 1) teams. One was interested and I presented findings to them. They concurred with these and were interested in additional data on specific questions they had about team functioning.

I shared findings with participants in Phase 2 specifically asking them to let me know if they disagreed with the findings or wanted to discuss anything further. These findings focused on aspects that may help them in their own co-creation activities. I also wrote a blog which I then shared with them. I will continue to disseminate to this group post-submission as all have expressed an interest in improving their co-creation activities or knowing factors that influence their own effectiveness.

3.9 Ethics

This study was approved by the NHS Health Research Authority (IRAS 188851). This study was part of a larger research application for organisation Deep. I was aware that this study, since it was exploring PHCP interactions, may elicit questions prior to approval. The sensitivity around such research with patients had been discussed in PI communities. I, therefore, provided the interview guide and had to clarify I would not be talking to patients in treatment, but rather those influencing healthcare systems. While this was true for all participants, it becomes a grey area especially if people (including HCPs) have long-term conditions. I was mindful of this throughout and it led to me exclude some of the public partners in initiative Jugat from being active participants in this research.

My research did not in itself cause harm to people but it did open a space where potentially sensitive matters were discussed. I was, therefore, prepared to provide a certain ‘duty of care’ so to speak. For example, Charlotte’s (Public) interview finished with her revealing some startling issues. Once I switched off the recording, I confirmed she was ok, safe, and had people around before I put the phone down. When I reflected on this with my supervisors, I suggested I should next time leave the audio on to prove I had provided a duty of care.

Anonymising

All data was anonymised by omitting names of individuals, locations, and organisations. However, it is likely that those close to this research may be able to recognise themselves or the improvement initiatives of which they were a part. Extra steps were taken to anonymise individuals where this was a concern and write ups were shared with these people.

I became aware of strong views held by some senior academics that research participants should be given a code rather than a name. Some stated this is because of pre-existing assumptions readers may make based on their experiences of people with the same name.

However, identities, roles, and essentially people were so central to this research. I therefore, decided to give pseudonyms. I used an array of names to present a sense of the diversity I feel we should aspire to achieve.

Continuing the influence of my own world view I anonymised names of organisations and improvement initiatives using both English and Punjabi words. These formed descriptors of the characteristics of the settings or people.

Data protection

All data was kept in line with the Data Protection Act 1998 and Imperial College London guidelines. Data was password protected. Transcripts were anonymised before being stored. Audio files were kept separately from transcriptions and data was given a code name. No data was stored on clouds and any memory sticks used were BitLocker protected. Fieldnotes were kept securely and not shared with anybody else. I used codes for individuals if they were discussing sensitive issues.

3.10 Conclusion

This chapter has described how this research was framed and conducted. It describes the participatory paradigm and the collaborative inquiry that formed part of this. It shared difficulties of implementing participatory research methods in busy healthcare settings. As such, this chapter highlighted how methods were adapted, including through the use of an ethnographic approach where findings were fed back to inform practice. Collaborative inquiry continued alongside this within organisation Deep. Case study design proved a useful way to capture a variety of experiences and practices across a range of settings. Interviews with improvement initiatives across the UK and internationally provided a valuable testbed for the findings that were emerging from the case study research. This, therefore, provided a useful way to test the findings across very different settings.

Chapters 4-7 present the findings from my research. Chapter 4 explores the importance of experiencing co-creation on its continued use. It highlights the roles individuals and wider systems play to facilitate this. Chapter 5 describes the longitudinal co-creation experiences in organisation Deep and the four case studies within this case. Chapter 6 uncovers the value of co-creation, and Chapter 7 shows how the use of QI methods influence co-creation.

4. Constructing a culture of co-creation: An experiential system

> "I wouldn't expect [HCPs] to understand straightaway. People are used to the old-fashioned way of working. And I think it's about education. It's about making them aware. It's about their experiencing it. It's about people being patient and…understanding the value that [public] team members bring to the project." **Cezary, HCP**

The literature presented in the previous chapters demonstrated that while PHCP working is encouraged and promoted, its practice and influence are variable. This way of working is complex, and its success is influenced by an interplay between contexts and individuals[88,91,95]. Supportive contexts include organisational structures and processes that can affect the realisation of practicable, effective PHCP partnerships[56,59,235]. These can facilitate or hinder how co-creators interact and build relations, which can be compounded when individuals such as public partners are positioned as passive or active co-creators[56,59,91,95,212]. The literature, therefore, presented multiple factors that influence co-creation. These factors portray a complex picture, which may provide more problems than solutions for optimising PHCP working.

This chapter seeks to provide some transferrable and generalisable answers for those who want to improve how the public and HCPs co-create for healthcare improvement and addresses the overarching research question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

and the sub-question:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*

I use the empirical data I collected to describe the supportive systems for co-creation and explain how individuals navigated PHCP working.

This research introduces co-creation as an experiential process that can be facilitated by supportive systems for co-creation. Existing research has described the experiential knowledge that public partners, in particular, bring from interactions with healthcare systems and health conditions[61,212,345]. Some literature describes interactions between the public and researchers as sources of learning and an experience that can change researchers' practice[96,106,346]. Staley and Barron (2019) focus on the quality of interactions and explore whether these lead to a change[96]. Nevertheless, PHCP working for healthcare improvement "needs careful management to realise its full potential"[78]. Value co-creation literature states factors that enable co-creation to realise its full potential include designing surrounding systems[82,86,88,279]. These systems facilitate co-creation by supporting and enabling individuals to actively engage in the process[82,86,88,279]. My research describes supportive systems for PHCP co-creation, how improvement organisations have created these, and the impact this has on PHCP co-creation.

This chapter introduces the first application of Ramaswamy and colleagues' Dialogue, Access, Reflexivity, and Transparency (DART) model as an explanatory theory of the experiential nature of co-creation[82,86,88]. They state that the four DART components are necessary for quality interactions between individuals and the surrounding contexts[82,86]. These components then create unique and personalised co-creation experiences for the individuals working together, which increase the likelihood that co-creation realises value[82,89]. This research defines and applies DART to describe what each of these necessary components is in relation to PHCP co-creation. In doing so, this chapter introduces the "building blocks"[82] of PHCP co-creation. It, therefore, offers a generalisable solution to construct supportive systems for PHCP co-creation.

Existing research states clear roles for public partners in particular are important to enable them to be meaningfully part of the process[56,78,206,279]. However, there is little research exploring what these roles could be for healthcare improvement. To further this research, I use my data in a novel test of Nambisan and Nambisan's (2013) roles for citizens in public sector co-creation[279]. Nambisan and Nambisan (2013) describe four roles the public can play in problem-solving and public service innovation: Explorers, Ideators, Designers, and Diffusers[279]. This chapter tests the applicability of these roles for PHCP co-creation, and provides the first exploration of these positions in the context of healthcare improvement. My analysis of all the empirical data I collected tests whether Nambisan and Nambisan (2013) provide an extensive list with their four roles and what this means to HCPs' place in co-creation.

This chapter is structured as follows. It briefly introduces the contexts in which this research took place and describes supportive systems that were created that facilitated co-creation. It then introduces the experiential nature of PHCP co-creation and how Ramaswamy and colleagues' DART model[82,86] offers an explanatory theory. Finally, I introduce the roles individuals played in co-creation, applying and expanding Nambisan and Nambisan's (2013) co-creation roles[279].

4.1 Designing supportive co-creation systems

This sub-section reports results describing characteristics in the surrounding systems that enable them to support co-creation.

4.1.1 The importance of context

Data were captured from improvement initiatives in a range of healthcare and related contexts mainly across the United Kingdom, with some examples from the USA, Sub-Saharan Africa, and Eastern Europe. Some data were collected from community settings and how this context influenced the structure and implementation of PHCP co-creation will be described in sub-section 4.1.2.

The majority of the data came from traditional healthcare settings such as hospitals, primary care settings and so forth. Additionally, data were captured from healthcare improvement organisations that worked across these settings and will be explored in sub-section 4.1.3 onwards.

4.1.2 Community Settings

PHCP co-creation was successfully facilitated in community settings with existing community networks and structures. These included established community structures that created ways of working with specific groups of people in Southern Africa, or existing networks that facilitated PHCP co-creation in geographic communities in parts of the UK. These community networks and structures were used to varying degrees as conduits between traditional healthcare settings and individuals in the community to improve healthcare in all the examples collected. The public and HCPs in improvement initiatives could, therefore, engage particular target groups in more familiar settings, using recognised methods:

> "[the improvement initiative] arranged…one of the meetings [as a]…kgotla [which] is the community meeting in a… little village… and that's where they meet and discuss issues of interest. So I was there at one of those meetings, and what shocked me was they had

> everything you could think of, traditional dancers, they had sports groups… and that's what represented the community system… you'd got all these different people who are all, in one way or the other, engaged." **Serj, HCP**

Such examples demonstrate that inclusive PHCP working was facilitated by a combination of community settings and improvement initiatives that were responsive to existing traditions and practices.

The small number of improvement initiatives that the public and HCPs stated were coproduced often took place in the community setting. The fact that some of these initiatives "start[ed] from coproduction and start from the grassroots up…" (Baljeet, HCP) was an important factor in their scope and wider perceptions of success. There were examples of initiatives that had received funding because of the commitment to coproduce, highlighting the popularity of this approach to funders. The data showed that coproduction was an inherently different way of working from HCP-led healthcare planning and delivery, and demonstrated it required a level of active participation. For example, Charlotte (Public) mentioned "not all of my work is coproduced. A lot of my work is presenting and meeting" thereby distinguishing between her more actively working alongside HCPs and changing how healthcare was delivered. Another factor that defined whether coproduction took place was the public and HCPs being positioned as equals. For example, Grace (HCP) saw public-led improvement initiatives as evidence of coproduction. Therefore, such working was deemed to challenge traditional power dynamics, but was positioned as one approach to PHCP working, rather than a catchall concept or term. However, not all the data captured in this thesis was deemed to be instances of coproduction by the public or HCPs who shared the examples.

Community-based healthcare improvement is challenging. Experiences from across the settings highlighted that it required time, resources, and reflexivity of the approaches used to bring together the public and HCPs, and was not always successful. For example, initiative Samaaj aimed to improve self-management for a chronic health condition through peer-led education across two geographic communities (5.5.5). The initiative was able to establish processes to realise its aim in one of the communities, but plans were hindered in the other community because of the lack of community infrastructure and the absence of local networks. Not all communities, therefore, equally facilitated PHCP co-creation for healthcare improvement and this warrants further research.

4.1.3 PHCP Co-creation: Not always normal practice

Participants were motivated to work together, but PHCP co-creation was not always normal practice. The motivation for public and HCP participants in this research came from a collective drive to improve healthcare. Many commented that there should be good quality healthcare for everyone, without a “contrast…between world-class care… and care that was frankly abysmal” (Taylor, Public). Some participants felt co-creation could tackle this variation and improve healthcare, which reinforced the resolve of these public and HCP participants to work together to improve healthcare. There were many examples, through observational and reported data, of clinically-practising HCP participants who embraced collaborative working and regularly worked with the public. However, there was significant concurrence from these participants who worked in primary care and acute settings that their practice to “engage people [and families] that use our services…is unusual” (Dave, HCP). This practice was unusual when compared with colleagues from the same clinical specialty such as primary care and paediatric medicine, who did not co-create with the public.

The priorities of existing healthcare structures and organisations were seen to influence the public and HCPs’ ability to work together. The NHS in particular was presented as target-driven rather than people-focused. Salima (Public) stated “…targets are important. But sometimes I think they allow patient experience to deteriorate. Because people are obsessed by meeting their targets.” This reinforced a perception that centrally defined requirements were prioritised above localised improvement. Surrounding structures were not seen to facilitate co-creation or improvement, and neither of these were seen as systemic norms in the NHS:

> “one of the things that struck me was that there were lots of efforts being made in the NHS…to…urge people to do improvement, but the system was…and…still is set up to do no improvement” **Chris, Public**

> “[Co-creation is] not normal practice. It’s not expected practice and… it’s still seen as a fluffy nice thing to do if you’ve got the time and the money and the energy. It’s not something that people see as normal at all. I wish it was.” **Paula, HCP**

A mandate for co-creation or improvement was not enough to make it happen as the design of existing structures, spaces, and practices often impeded improvement and co-creation becoming the norm.

There was evidence of HCPs who resisted or were sceptical of co-creation. These were reported or observed examples of HCPs who chose not to share their experiences as part of this research. Observations highlighted these HCPs would either ignore or avoid working with the public (Fieldnotes: 09/12/2016), with reported data describing them actively challenging co-creation. Both public and HCP co-creators described the challenges of changing the mind-set of these HCPs to engage them in this way of working:

> "the challenge…is to get your sceptic into a position where they really do work shoulder to shoulder… the problem is that some of the sceptics just aren't willing to work in that way. They don't really work shoulder to shoulder because they're often your monocratic individuals who don't really believe in the value of consultation and collaboration."
>
> **Astrid, HCP**

Co-creation, for some, presented a challenge to their normal practice. Further research with these sceptics could provide interesting insights to better understand this resistance.

4.1.4 Expected roles and behaviours of the public and HCPs

The data, especially from UK healthcare settings showed the public and HCPs had, or were given, multiple identities that could influence their role in co-creation. Participants described healthcare practices that emphasised "professional boundaries… I'm a nurse, you're a doctor, you're a patient" (Chanan, HCP). Such practices could position the public and HCPs as dichotomous concepts and overlook the individuals' multiple identities. Examples highlighted that this influenced the perceived value of the public partners, and led to situations where they had to stress their professional identities to achieve gravitas:

> "It is one of the rare [initiatives] that I confess to being a professor on… actually, that started off as a glib remark, but there is the issue of face… there's a sense that people may take me more seriously… But that's one place where I do find being Prof a useful way of being heard to show I want to say something." **Aled, Public**

Similarly, HCP participants revealed experiences as carers or patients in healthcare settings that influenced how they viewed and practiced PHCP co-creation. Ajeet and Dave (HCPs) recalled negative experiences of being carers, or receiving care, that revealed to them the perspectives that the public can bring to shape healthcare. Wider identities were important factors of how the public and HCPs worked together but expected identities could overshadow the potential of individuals to the co-creation process.

An interrelated issue was that individuals were expected to work and behave in particular ways. The data demonstrated that this was the case for HCPs and the public, and in some cases, could lead to socialisation where public team members embodied passive, almost submissive roles. For example, Pete (Public) in initiative Connect (5.5.6) would exemplify subservient behaviour and put his HCP colleagues on a pedestal (Fieldnotes: 09/09/2016 and 11/04/2016). He embodied "quite a traditional patient-doctor role" (Tarrie, HCP), rather than being an active co-creator. This echoed other findings of "some services users who… like to be told what to do and don't embrace the more collaborative style" (Astrid, HCP).

Similarly, HCPs could place public team members in subservient roles. Ezra's experience highlighted that some clinical HCPs were more comfortable working with fellow HCPs than the public. These HCPs saw the public as passive recipients of care, and were less comfortable with them being active co-creators:

> "…the last two meetings I co-chaired it with a lady who's come from a very, very clinical background… there was an atmosphere…whenever I tried to take charge of that meeting, as I was accustomed to… she wasn't comfortable with this, me being on a level playing field… She knows I've got skills but I don't think she wants to respect those skills because in the NHS she wants me to behave like a patient and…go and sit in the corner and take your tablets. But that's not all the staff." **Ezra, Public**

Ezra's experience echoed my other data about perceived hierarchies between specific clinical and non-clinical expertise. These professional boundaries and related hierarchies could reinforce siloed-working and exclude the public. This was reflected to a lesser extent by HCPs, who would not invite their public team members to certain meetings to discuss and advance the improvements (Fieldnotes: 11/03/2016).

4.1.5 Supportive structures for co-creation

Specific structures and spaces could facilitate co-creation for healthcare improvement. All examples from healthcare improvement-focused organisations described PHCP co-creation as a core part of their approach and processes: "you can't be an improvement organisation and not resource [co-creation]" (Astrid, HCP). This enabled both public and HCPs to experience working together even if in wider contexts “patients and families have not been as involved as they do become when we start to design the programmes” (Dave, HCP). All the clinical HCPs who embraced co-creation had been previously exposed to working with the public, apart from Rita (GP). This exposure was from programmes that facilitated healthcare improvement and were external to the organisations in which they worked:

> “as clinicians… we’re kind of incubated in hospitals but we’ll do one job followed by another followed by another and that’s our world… I did [national healthcare improvement organisation] course which again has a heavy focus on patient involvement. But thereafter I… got more ideas in terms of how this could be done.” **Ajeet, HCP**

These improvement-focused organisations could therefore create a culture of co-creation and support the practical realisation of PHCP working.

The following case study from organisation Ekta provides an example of how these healthcare improvement organisations create spaces and embed processes that facilitate PHCP co-creation. Health and care organisations in a specific geographic region paid Ekta to teach and support them to improve practice. This case description triangulates the experiences of HCPs: Astrid, Paula and Aisling, and the public: Ezra and Niamh, along with documents explaining Ekta’s approaches.

4.1.6 Organisation Ekta: Constructing a culture of co-creation

Ekta was committed to both healthcare improvement and PHCP co-creation. Initially, the organisation was formed solely of HCPs with limited PHCP co-creation. This small core HCP team had expertise in QI and healthcare delivery, and the organisation and the programmes they ran were “very acute-focused… and very hierarchical” (Astrid, HCP). Some senior HCPs in Ekta became advocates for co-creation from their previous experience of working this way. This included Astrid, who explored how co-creation could work in practice with some of the public she knew. Astrid and Ezra (Public) initiated processes to recruit and enable a diverse group of public partners to work with Ekta. They brought personal experiences of using mental health services, and having or caring for people with chronic conditions. The public partners had professional experiences in financial services, construction, and healthcare and were paid, trained, and supported to lead and facilitate healthcare improvement.

The public team members were trained to teach teams about QI methodologies and co-creation. They participated in and facilitated learning spaces to support largely HCP-led teams funded and supported by Ekta to plan and shape improvements. The physical presence of Ekta public partners as improvement experts in these spaces enabled them to humanise co-creation and demonstrate to HCP-led teams the potential of QI. The public partners used QI methods to support the HCP-led teams to conceptualise improvement problems and plan solutions, including future PHCP co-creation. For some of the HCPs this new approach went against the traditional way of working. HCPs sometimes had preconceived ideas about how the public should work with them and were perplexed by the presence of these public partners:

> "… another person running a programme for middle managers… said "can you come in and do a two hour slot?" And I said "no… I'm there for the day, because it's got to be done in the context of the overall work. I don't want to just be rolled in to do… the bit about patients…" But actually when I said no I'm not going to do a two hour slot, we had a conversation about why not, and so I've now been for the whole day and we've done a bit more work on what's happening with the overall programme. But that was a bit slower getting started, if you like, and it's taken a bit more convincing." **Niamh, Public**

The Ekta public partners also led improvement initiatives, such as using staff and patient experiences to redesign mental health services. A small group proposed the idea to multiple healthcare organisations and settings. They then facilitated the whole improvement process with an interested acute trust. The public partners were seen to be delivering something needed and modelled co-creation throughout the improvement process by engaging trust patients and staff:

> "[The management] thought it was the best thing since sliced bread when we presented it to them… They want this now implemented across every single service line. And… it got the staff engaged because from day one they thought, "our opinion counts here". And I try and do that a lot." **Ezra, Public**

Ekta, as an organisation increased their capacity to deliver improvements by supporting and enabling the public partners to lead QI. Through this, they challenged assumptions of the roles of public partners held by individuals in their partner healthcare organisations. Even within this seemingly progressive case study, there was resistance to co-creation, internally and externally, in other local organisations and systems.

Data from Ekta highlighted two other interconnected challenges to co-creation, firstly the desire to maintain the current status quo, and secondly, concern regarding transparency and confidentiality. The individuals in Ekta had experienced public and HCPs who challenged co-creation because they appeared content in a paternalistic system. Astrid (HCP) shared examples of public who did not want to actively co-create and felt decisions should be left to HCPs. Some interviewees spoke of HCPs who appeared content with current power imbalances that gave them authority over the public. This connected to the worries that some HCPs had regarding transparency. Aisling (HCP) felt this explained the strongest resistance to co-creation from within the organisation and externally:

> "There are still aspects where it feels it's tokenistic and it's done because we need to do it not because it's the right thing to do."
>
> [Interviewer: Why?]
>
> "Because they are frightened to death about airing what they perceive to be dirty laundry and how [the public] will… hear that and how, and whether it's appropriate." **Aisling, HCP**

Thus challenges to co-creation could be systemic and influence organisational attempts to enable and enhance PHCP working.

4.2 Co-creation as an experiential process

This sub-section presents the impact of experiencing co-creation, introduces Ramaswamy and colleagues' DART model[82,85,86] as core components for these experiences, and demonstrates these two factors through two in-depth examples of PHCP working.

4.2.1 The Virtuous Cycle of Co-creation

My findings showed people needed to experience co-creation to understand the potential that PHCP working could realise. This could require mandating PHCP working and providing resources and support for this way of working, as the organisation Ekta did in sub-section 4.1.6. This enabled PHCP to come together and work towards a common purpose, which was to improve healthcare. It facilitated interactions that initiated dialogue and enabled the public and

HCPs to build relationships through experiences of working together (Chapter 5). Ultimately, these interactions enabled them to connect as people and see the potential of working together:

> "…just over a cup of coffee I said, "oh, Ezra's (Public) got experience of that" and introduced Aisling (HCP) to [him]. [They] hit it off…. They designed the presentation together. They did all sorts of different things and that one introduction turned Aisling's head… she's one of the biggest advocates of [co-creation]…now." **Paula, HCP**

The above quote shows that experiencing PHCP co-creation increased the likelihood that some value was realised for the individual co-creators. They could advance their own knowledge base, or mentally engage with a task, or socially engage with others through co-creation. Co-creation itself could be deemed value when it enabled PHCP to co-deliver healthcare improvements.

My findings show PHCP were more likely to see co-creation as a useful way of working if they realised value through it. The value realised from co-creation is expanded in Chapter 6, and could be for individuals, organisations, and society. Realising value for the individuals involved in co-creation could be useful to persuade sceptical HCPs:

> "The only way I think you can convert people is when they actually see for themselves and they see the impact and it can be quite sort of transformational for them."
> **Astrid, HCP**

Experiencing co-creation and realising value enabled individuals and organisations to see the potential of PHCP working.

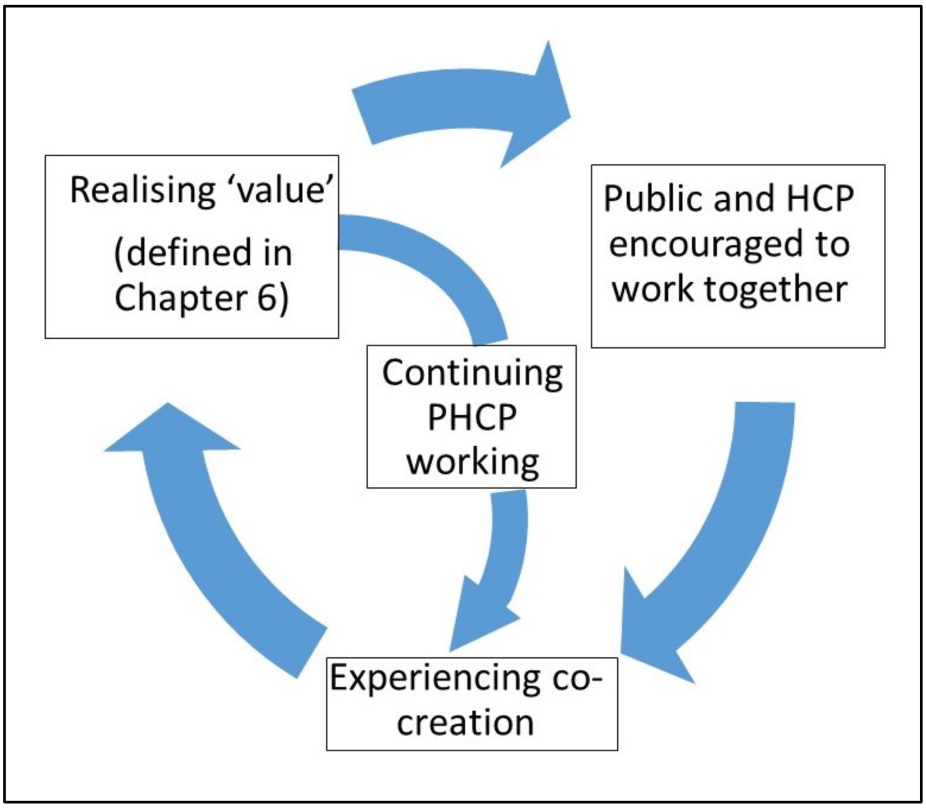
Both experiencing PHCP co-creation and realising value from this process could encourage people to continue working together. There was substantial evidence across all the organisational case studies that this happened for HCPs in particular. These factors helped to demonstrate that co-creation was a necessary and useful part of healthcare planning, delivery, and improvement, and as such HCPs were likely to consider and continue PHCP co-creation in the future:

> "…the [improvement] Fellowship definitely exposed me to the benefit of having patient engagement and what it meant and then I started to do it and I'm converted. I couldn't do it any other way now..." **Chanan, HCP**

Additionally, co-creation experiences inspired some HCPs to change their relationship with their own patients and become more collaborative healthcare professionals (6.2.1).

These findings, therefore, corroborated Wilson et al.'s (2015) results showing "PPI activity became a self-sustaining virtuous cycle"[235]. In the context of my research, a virtuous cycle of co-creation had three interrelated parts: experiencing co-creation; realising value; and continuing PHCP working (Figure 12 adapted from Wilson et al., 2015).

Figure 12 Virtuous cycle of co-creation



This also echoes Ramaswamy and colleagues' research describing how unique co-creation experiences realise value[86,89,109], and therefore warrants an explanation of how such experiences are created.

4.2.2 The experiential nature of co-creation

Ramaswamy and colleagues describe Dialogue, Access, Reflexivity, and Transparency (DART) as the building blocks of co-creation[82,86]. DART facilitates engagement and interactions between individuals and surrounding systems[86,88]. This then creates unique co-creation experiences that realise value. DART can offer a useful theory to explain the quality of PHCP interactions and describe how co-creation's experiential nature is realised. Table 7 presents Ramaswamy and Ozcan's definition of DART from their data from businesses[86], alongside how each element was evidenced through PHCP co-creation in my research.

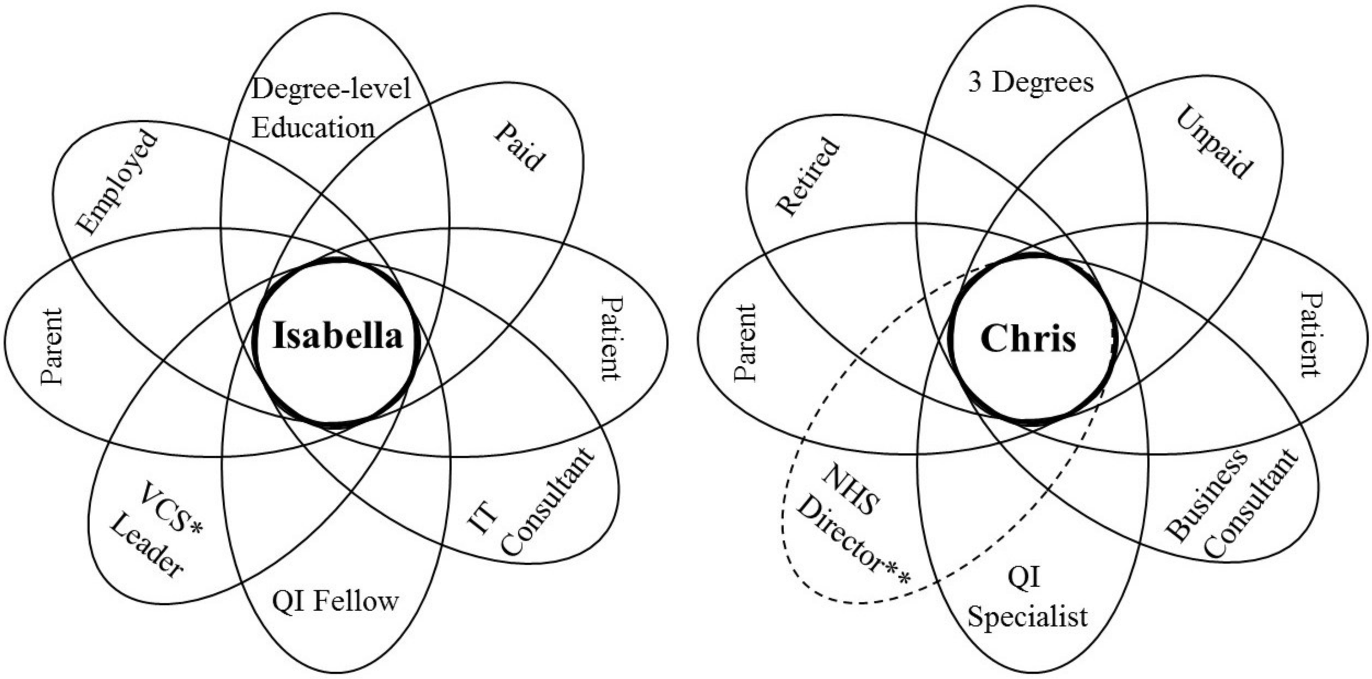
Table 7 Definition of DART from my data

	Definition based on Ramaswamy and Ozcan (2014)[86]	**How this manifested in PHCP co-creation**
Dialogue	Between equals through active conversation & sharing views of what is meaningful to individuals	Dialogue between public and HCP enabled them to shape healthcare improvement. The public were often invited into healthcare and related settings and processes in which they may not otherwise be included.
Access	Gaining information about experiences, context, tools, expertise, skills etcetera of other agents	Both Public and HCP partners gained information about healthcare experiences and processes. HCP and sometimes public would learn about and access tools and expertise that supported co-creation for healthcare improvement.
Reflexivity	Achieving better co-creation by feeding back learning from co-creators, and structures that facilitate co-creation.	Public and HCP would reflect on both the co-creation process and the proposed healthcare improvements, adapting these as needed. This was a strong characteristic in the six organisational case studies.
Transparency	Visibility of information. Implies openness and communication that builds trust.	Transparency of healthcare and related organisations and the purpose of co-creation, was necessary to enable both public and HCP to fully engage. This happened at varying levels.

PHCP co-creation was a complex, dynamic process partly because of the various contexts in which it took place and the different individuals who were part of the process. This is demonstrated through the co-creation experiences of two public participants described below (Isabella: 4.2.3 and Chris: 4.2.4). Both highlight the importance of public and HCPs experiencing co-creation and realising value from this approach. But Chris and Isabella's experiences also showed how components of DART, or their absence, can explain the quality of interactions and what is achieved through co-creation.

These two individuals were chosen because they provided comparable examples and appeared to be equally adept, confident, and eloquent, and have similar professional and patient experiences (Figure 13). These factors enabled them to strategically position themselves to influence healthcare improvement. Isabella and Chris highlighted some struggles and demonstrated that co-creation for healthcare improvement is influenced by more than the individuals involved.

Figure 13 The multiple identities of Isabella and Chris



* - Voluntary and Community Sector

** - Interim, short-term role

4.2.3 Isabella: Instrumental internal influence

Isabella described a variety of PHCP co-creation activities that aimed to improve the quality of life, including through better healthcare planning and delivery, for people with a chronic condition. Isabella had experience of living with this condition. She had additional characteristics and skills that appeared to make her ‘the right type of patient’ for HCPs as demonstrated through this case. Isabella progressed through a ‘co-creation pathway’ where one opportunity would lead to or initiate the next co-creation opportunity.

Isabella initially participated in unpaid co-creation activities in her local hospital-based group focused on raising awareness of the chronic condition. She quickly moved from being a participant to chairing that group. Isabella was then asked to chair meetings of a collaboration of organisations focusing on the chronic condition across the UK. Some strategically-placed individuals in the collaboration recognised Isabella's commitment and value and set up a structure that enabled her to take a paid leadership position. This demonstrated the value of Isabella's position to herself and others, and reinforced her commitment to co-creation and healthcare improvement:

> "I was able to feel better for myself that I was giving that time and it showed the value that that group placed on me as…its ambassador that could go out and about speaking on everybody's behalf." **Isabella**

Since then, Isabella has continued to lead organisations that focus on improving the lives of people with the condition. Her roles have included designing and managing improvement initiatives, including those focusing on self-management. Additionally, she provided strategic oversight for initiatives where the public and HCPs are working together to improve healthcare.

Isabella's experiences highlight PHCP co-creation varied and was a considered process. She described various ways that PHCP co-creation occurred. This included PHCP working together to establish peer support initiatives, coproducing interventions to improve patient-reported outcomes, or provide strategic oversight together through programme boards. Activities ranged from the public and HCPs working together regularly to implement healthcare improvements to more sporadic collaborative working. Therefore the public and HCPs engaged in frequent dialogue and reflexivity when working together regularly on tangible improvements, and had varying levels of access to information. Isabella's experiences highlighted PHCP working together actively and regularly required careful management. Isabella mentioned a group of PHCP who had never worked together in this way before. The group experienced "a lot of norming and storming" (Isabella), and required time to build trust and establish relationships to find an effective way of working together. Therefore, the beginning of the initiative was spent initiating dialogue and reflexivity to manage tension and team dynamics rather than initiating healthcare improvements.

Isabella warned that co-creation could mean "a token patient…invited in so that a box can be ticked". Her experiences highlighted the necessity "to actually link the right patients, to the right healthcare professionals, in the right projects because just saying we'd like some patients to help with this thing doesn't [work]." Isabella tackled this by managing, directing, or otherwise shaping PHCP co-creation with her approach reflecting the DART components. Experiencing and seeing Isabella co-creating alongside other public and HCPs strengthened other individuals' resolve to adopt this process. This created further opportunities for Isabella, increased her profile, and reinforced co-creation as an underpinning way of working. The fact that this way of working was deemed successful by others outside of Isabella's organisation further strengthened their resolve to work in this way:

> "[The funding organisation said they were] very, very pleased with the way that… the patient group had interacted with the rest of the group, and the members of the patient group itself felt that it had been an extremely rewarding experience for them." **Isabella**

This perceived success was useful to reinforce co-creation as a valuable way of working.

4.2.4 Chris: External expertise and co-creation

Chris was a retired business consultant who had brief experience at a senior level in a Primary Care Trust. He supported organisations to improve through his own consultancy. This spurred Chris' post-retirement interest in improving healthcare. He established a profile for himself and used this to connect with relevant HCPs. Chris was then invited to participate in nationally and locally-focused healthcare organisations. Locally, he was a public partner with a Clinical Commissioning Group and aimed to improve primary care in the area that he lived.

Chris encouraged the organisation to take a structured approach to improve healthcare, including embedding improvement practice and working with the public. This required the organisation to commit to a level of transparency and reflexivity about how they worked. Soon after starting to work with the CCG, Chris created and led a patient experience survey. This survey highlighted his potential value and strengthened his place within the organisation. "The survey…was statistically valid and set up in such a way that everybody was looking forward to the results, and it had quite a profound impact on the practice" (Chris).

Chris's extensive experience supporting organisational change enabled him to acquire theoretical knowledge and practical experience using QI methods. His experience of improvement methods was greater than some of the HCPs in the CCG. Chris believed taking a QI approach to healthcare improvement would provide methodological rigour: “there’s something profoundly different that can be made to happen if you’ve really genuinely got patients involved, and it’s set up as a proper scientific study.”

Chris highlighted a lack of reflexivity could limit the improvements the CCG realised. He stated “each year I try and get [the organisation] to insert stuff around improvement, and each year they talk themselves out of doing it and carry on as before.” His experiences and knowledge of the interactions between local and national organisations had highlighted a tension between what was required and what was desired. What was required was often centrally controlled by organisations and powers somewhat removed from the local context. What was desired was what local public and HCPs wanted to happen. Chris felt local organisations would prioritise the required over the desired. He felt the questionable organisational commitment to improvement was an example of this: “[the CCG] don’t really see their job as something that is creating…continual improvement, and are not even sure what that is”. However, occasionally the required and desired aligned and public partners were able to use this to drive changes they wanted to see. For example, the patient experience survey Chris led highlighted patients wanted access to their medical notes. The HCPs at the organisation consistently denied permission for this to happen. Eventually, access to medical records became a national agenda and the organisation consequently supported work to achieve this.

This tension between the required and the desired led Chris to work outside of healthcare organisations to improve the system. He grew increasingly frustrated by what he saw as the limitation on improvement in practice and connected with likeminded public and instigated parallel improvement initiatives. He became a conduit between the organisation and other public for initiatives bringing together groups of public to work with HCPs, and facilitated the process. Chris stated one initiative in particular was well received by HCPs and its success encouraged them to participate:

> “It’s got so much interest from one or two people in the CCG that the Head of Engagement… has decided she wants to co-facilitate that with me because…it’s the most exciting thing she’s seen.” **Chris**

However, some of the public then decided they wanted to coproduce the organisational report on quality. This was not supported by HCPs in the organisation who felt it would be a difficult process. While the CCG did not want to coproduce the required monitoring reports, they saw value when Chris initiated quantifiably demonstrable improvement initiatives, for example, the statistically valid patient-experience survey. The public partners, therefore, decided to work on their own to carry out this work. This situation showed standard methods that exemplified accepted practices were more acceptable in this CCG.

The examples above demonstrated DART provided a useful explanation of quality interactions between the public and HCPs. The DART components underpinned the unique co-creation experiences that manifested and enabled value to be realised from this way of working through enhanced commitment to this process. Both Isabella and Chris's experiences showed the public and HCPs formed and evolved relationships over time. Yet time did not always lead to increased dialogue and transparency. Chris's experiences highlighted that the public was not always positioned in ways that increased their influence for healthcare improvement.

The flexibility or rigidity of organisational structures and the level of transparency in existing practices could influence how co-creation happened in practice. Normative organisational arrangements such as traditional governance structures were replicated in Isabella's experiences and challenged in Chris's. Chris's experience shows the rigidity of organisational structures and practices could impede the influence of the public. Isabella highlighted that working within these "invited spaces" could provide validity to co-creation although it was unclear whether this came at any expense.

So how can people best navigate and optimise co-creation experiences when there are so many variables? One approach could be to take on specific roles, as discussed in the next sub-section.

4.3 Roles for individual co-creators

My research found that the public and HCPs could disengage from the co-creation process if they were uncertain about their or other co-creators' roles. For example, HCPs uncertainty about what the public would do in healthcare improvement could lead them to challenge their inclusion in the process. Astrid (HCP) noted that some of the HCPs in improvement initiatives she worked with asked “why should I be spending my budget to fund somebody just coming and sitting for an event?” Even where HCPs were motivated to work with the public they sometimes struggled to know how to involve them in explorations of future work and theoretical healthcare processes (5.5.6;5.5.7). That the public had not experienced these theoretical processes added to the uncertainty about the roles they could play (7.4.2).

Additionally, uncertainty about HCP roles in co-creation influenced their interaction with healthcare improvement. Some HCPs became passive in the improvement initiatives when they were unsure of their responsibilities and felt they were not contributing. They could stopped attending improvement-focused meetings or become spectators rather than co-creators (5.5.6). This arose because of the uncertainty created through vague roles, which were difficult to define when this was part of a new way of working.

My results showed that when co-creators had specific roles they could better navigate their place in this process and establish effective ongoing working relationships. The transparency about individuals’ responsibilities alleviated tension between team members (5.5.5). This corroborates other research emphasising the importance of defining public roles in systems change initiatives[78]. Nevertheless, there remains little research describing the roles that the public or HCP co-creators take in healthcare improvement initiatives.

Nambisan and Nambisan’s (2013) four roles for citizens co-creation in public service innovation[279] could offer potential for PHCPs. They describe Explorer; Ideator; Designer; and Diffuser as roles that relate to specific phases of innovation and are presented in order of that process[279]. My research found that these roles existed for the public *and* HCP co-creators in healthcare improvement. Furthermore, my findings demonstrated four additional roles for the public and HCPs in the healthcare improvement context, Advocate; Gatekeeper; Connector; Benefactor. These eight roles provide examples of how the public and HCPs participated in healthcare improvement, and are presented in the order in which they happened during the co-creation process. These roles are defined from the data collected through this research and presented in Table 8. The definition of the roles describe how they manifest in health and related contexts in traditional and community settings as introduced in sub-section 4.1.1. The examples of these roles came from the UK, the USA, Sub-Saharan Africa, and Eastern Europe.

Advocate and Gatekeeper roles influenced and shaped the environment in which co-creation took place. Ideator and Designer roles positioned individuals as active co-creators engaged in the process of improvement. There were fewer examples of Benefactors and Gatekeepers but where present they influenced co-creation and merit inclusion. Connectors and Diffusers were roles held by public co-creators and enabled them to spread innovations and strengthen relationships. Therefore, all the roles played a part in enabling the right environments or facilitating individuals to co-create healthcare improvement.

Table 8 Roles of co-creators

Role	Definition
Advocate	Use positional power to encourage and enable co-creation
Gatekeeper	Enable access to individuals & systems, and can regulate when and how co-creation happens
Explorer*	Highlight areas for improvement from experiences of healthcare
Ideator*	Conceptualise potential solutions and suggest avenues to take this forward
Designer*	Design, influence or implement improvements and/or facilitate the delivery of improvement initiatives
Diffuser*	Adopt or diffuse innovations and influence the scope of healthcare delivery or the improvement initiatives among specific populations
Connector	Actively connect individuals with each other and healthcare systems
Benefactor	Provide resources for improvement initiatives or healthcare delivery

*Adapted from Nambisan and Nambisan (2013)[279] with definitions based on the data analysed as part of this PhD

The eight roles of co-creators described in healthcare improvement, through this analysis, are independent and interrelated and can be fluid rather than distinct, forming parts of an ongoing co-creation process. For example, in specific situations, Explorers became Ideators and move from conceptualising problems to conceptualising solutions. Additionally, one role could facilitate another role. For example, Advocates in organisation Ekta created an environment that placed the public as Designers working with HCPs to actively shape improvement initiatives. It is important to see the roles as components of an ongoing and complex co-creation process and all roles of potential importance depending on the context, timing, and the individuals involved.

Interactions between the public and HCPs supported individuals to be effective in co-creation roles. Individuals acting alone could not always influence improvement. Conversely, specific HCPs were seen to influence both commitment to co-creation and healthcare improvement and could be needed to motivate other individuals, and shape environments for co-creation (4.1.6). Similarly, the public could influence the direction of healthcare improvement and attract strategic buy-in (b). Public and HCP co-creators needed to interact with other people and healthcare systems to optimise their influence. The data showed PHCP interactions enabled individuals to bring together a combination of experiences, knowledge, skills, and motivations.

The eight co-creation roles outlined in Table 8 are now described in more depth.

4.3.1 Advocate (new role)

Advocates were predominately HCPs who were able to encourage other colleagues to work with the public. The results show HCPs in this role were respected individuals within their organisations, often senior leaders or perceived as having authority. They used this influence to build more acceptance of PHCP co-creation. The six organisational case studies revealed that Advocates' influence could lead to the creation of specific roles and commitment of resources to facilitate co-creation. In turn, co-creation became an advocated way of working within an organisation (4.1.6; 7.1.2;5.5.2.1).

While there were examples of the public being positioned as Advocates, the data showed their influence on healthcare improvement was more limited (4.2.4). Additionally, both interviews and observations highlighted senior HCPs who were indifferent to co-creation and did not become Advocates. These HCPs required evidence that co-creation was a useful way of improving healthcare, and this could limit the creation of a fertile co-creation environment that influenced healthcare improvement.

4.3.2 Gatekeeper (new role)

Gatekeepers influenced and controlled the practicalities of co-creation. They were primarily HCPs but there was also observational evidence of the public playing this role as described in sub-section 5.5.6. Gatekeepers controlled physical spaces and co-creation activities. In traditional healthcare settings such as hospitals, HCP-Gatekeepers enabled public to access meeting rooms or organisational spaces. In community settings, public-Gatekeepers would need to give HCPs permission to participate in traditional community meetings (4.1.2).

Gatekeepers managed who participated, existing organisational or community boundaries, and enabled or prevented co-creators from being part of healthcare improvement initiatives.

Gatekeepers could create boundaries around where and how co-creation happened. Some HCP-Gatekeepers would challenge the public's participation. Specifically, they would highlight situations in which they felt the public should not participate and thus created rules that managed when and how the public participated:

> "If care or service delivery is about people, how we can be so arrogant to perceive that people can't be involved in those discussions. And there is still that element, "well it's not appropriate, they won't understand or they won't hear". Well, then, actually our job is to make it appropriate, make it understandable..." **Aisling, HCP**

Observations showed the public could similarly create boundaries that exclude other public. During my ethnographic explorations with initiatives Connect and Jugat (5.5.6;5.5.7), some public partners would acknowledge the need for the improvement initiatives to understand different patients' experiences. These public partners would frequently be positioned as the patient or PI representatives and reinforced this by introducing themselves as such in initiative-related public fora. Significantly, when questioned by PI facilitators about who else they could work with, Pete (public, Connect) would reiterate "they've got me" [Fieldnotes, 20/7/2016]. Therefore, the public could become Gatekeepers and not actively look for opportunities to work with other public. This, then, reinforced "good enough" co-creation where an initiative felt how they currently worked with the public was sufficient to demonstrate a commitment, without exploring any further potential PHCP co-creation could bring (5.5.6).

4.3.3 Explorer and Ideator

Explorers conceptualise problems and Ideators conceptualise solutions[279], and my data showed both public and HCPs held these roles. My research demonstrated that in the healthcare improvement context, Explorer and Ideator roles were linked rather than being two distinct positions. These roles are, therefore explored together.

Individuals who were successful Explorers and Ideators used their own experiences, or awareness of other settings, to be more solution-focused. This enabled PHCP Explorers and Ideators to suggest new or different ways of doing something. Interactions between the public and HCPs enabled them to identify and define problems and solutions (7.2). Environments that allowed public Explorers to conceptualise problems tended to aid them to be Ideators and conceptualise solutions:

> "the child's mother had told us was that she would really have liked to have known the [test] result a lot earlier rather than having to chase these up herself [and] calling… so texting the results to the parents we thought would be a solution that would work." **Ajeet, HCP**

However, bringing together these different perspectives often required careful management and facilitation. Use of QI methods such as driver diagrams enabled both the public and HCPs to be Explorers and Ideators (7.2). These methods provided a facilitated, managed process that allowed the public and HCPs to air their experiences of different sides of the care process. This could enable the public and HCPs to more fully problematise and therefore accurately prioritise issues for healthcare improvement.

There were examples of less receptive environments to the public being Explorers and Ideators, thereby limiting their influence. Examples of this were when the public were involved at relatively late stages, including after initial solutions had been conceptualised. Salima (Public) highlighted "we're sometimes the tail end, an add on, as far as local involvement's concerned". Additionally, some organisations appeared defensive of their current work cultures and practices. This limited the ability of the public to influence change within the organisation. An example of this was Chris (Public) and fellow public colleagues' suggestion that they coproduce the CCG's regular quality report (4.2.4):

> "I got [a] note the following week saying, "there's no way we can cope with this…and…the answer is no, we're not going to let you do it". So that was an interesting response… I went back to the four others [public] that I'd been talking to about this over a number of weeks and they all said, which surprised me a bit, "this is so important we're actually just going to do it anyway" **Chris, Public**

Therefore, while the organisation's negative response did not perturb these motivated public partners, it did question the influence they had as Explorers and Ideators within the structure.

4.3.4 Designer

My research is based on observational and reported data found evidence of both the public and HCPs as Designers. Adopting Nambisan and Nambisan definition, Designers "design and/or develop implementable solutions"[279] for healthcare. Designers in healthcare improvement initiatives were also important for implementing solutions, thereby expanding Nambisan and Nambisan's definition[279]. Designers encompassed a range of activities in healthcare improvement. For example, the public and HCPs, from the initiative Jugat, shaped the development of a healthcare app. They fed into the design, tested early iterations, and shaped how it could be used in practice (5.5.7). Other initiatives highlighted PHCP Designers shaping healthcare information. Community Health Workers (6.2.3) were an example of PHCP designing and implementing new healthcare delivery models. These were individuals who were members of specific geographic, social, linguistic or other communities who were conduits between communities and formal healthcare structures. These examples highlight the interconnected nature of planning and doing, rather than them being distinct roles with Designers only planning.

The public in particular influenced healthcare and improvement as part of their role as Designers. My results concur with Armstrong et al.'s (2013) findings that public could be a "*technology of persuasion:* a means of influencing opinion and debate"[78(p7)]. Public could be voting members of organisations and therefore use that power to influence. More commonly, the public's physical presence in spaces aimed at improving healthcare was likely to influence outcomes and hold HCPs to account (b). This created a slow shift towards a culture where the public were seen as useful agents. As Salima (Public) stated "the biggest change I've seen in the 20 years is clinicians really happy to have you there, and happy to learn what has been of importance to patients." The public's physical presence also allowed them to influence written or digital communications, such as patient leaflets or text messages. The public's influence therefore went beyond opinion and debate, and achieved tangible changes.

Public Designers were also facilitators and implementers of healthcare improvements (4.2.3;4.2.4). As such, Designers' role went beyond designing and developing implementable solutions to facilitating and implementing healthcare improvement interventions or innovations. For example, the public designed and implemented new ways of collecting patient experience data (4.2.4). Public Designers also managed and ran support groups to help peers better manage their conditions (5.5.5).

4.3.5 Diffuser

The public as individuals and communities were Diffusers across geographic, organisational, and professional boundaries. Nambisan and Nambisan (2013) state this role "underlines the contributions that citizens can make in helping their peers adopt (or use) new services."[279(p14)] Examples will be discussed in greater depth in Chapter 5 and 6.2.2, with a brief overview provided here.

This research found Public Diffusers were useful in scaling up as well as passively spreading innovations and interventions. CHWs scaled-up interventions by screening members of target communities. The public also extended the boundaries of improvement initiative beyond what was initially planned:

Project Connect's team meeting

Pete, the public team member, had had some interest from a group in [Old Town], which is outside the geographic scope of this project. He didn't seem to mind - he is going to work with them to show them the [innovation]. It hit home that public can, and do, work outside of the priorities defined by organisational or financial structures. They have the enthusiasm and ability to do this whereas HCP team members tend to be more confined to boundaries set by the parameters of the organisations and defined project aims.

Fieldnotes: 24/3/2017

Public Diffusers passively spread tangible healthcare innovations to other public and HCPs. The strongest examples of this came from the longitudinal explorations of initiatives Woke and Connect (5.5.4; 5.5.6). The public in both projects made the most of serendipitous interactions with HCPs and other public. They would actively use the innovations themselves and show them to other public or HCPs during chance encounters in lifts, or at meetings and events. This corroborates Renedo et al.'s findings that demonstrated the role of public partners in the spread and sustainability of healthcare improvements and innovations[37,114].

4.3.6 Connectors (new role)

Public Connectors could be conduits between healthcare services, improvement initiatives, individuals, and communities (Figure 14, pg.118). Public co-creators' shared characteristics with other public or target communities which could facilitate their role as Connectors. Characteristics included living in the same geographic communities, having the same health conditions or speaking the same language. This familiarity helped build relationships and establish trust. This connects other public or target communities to improvement initiatives or healthcare services that were relevant to them:

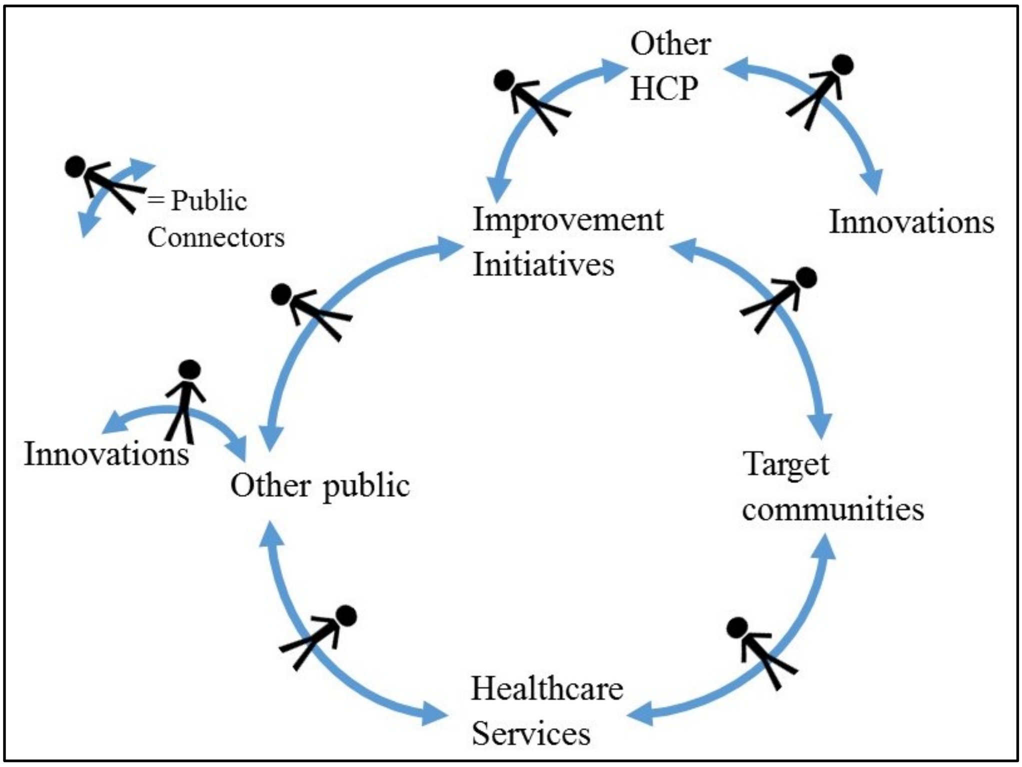
> "The team will keep track with the provider at the facility who's come and who hasn't come… In [Southeast African country] for instance… they found that there were women, from a certain religious community who were not going for antenatal care, so that they were able to go reach out to the pastor." **Arundhati, HCP**

Public Connectors also brought knowledge from individual public or communities into the initiative to inform healthcare services design.

Interestingly, Public Connectors were conduits between core improvement initiative team members and other HCPs. While these HCPs were not part of the core improvement team, they were useful to achieve the initiative aim for example, they needed to be engaged to help the initiative screen for health conditions (5.4;5.6).

Continued overleaf.

Figure 14 The connections made by the Public



4.3.7 Benefactor (new role)

There were two examples of the public acting as Benefactors for healthcare improvement from initiatives Connect and Jugat (5.6;5.7). While the number of examples is few, they provided significant resources for healthcare improvement.

Public Benefactors enabled improvement initiatives to achieve core deliverables or provided supplementary healthcare support mechanisms. For example, Pete (Public) gave significant amounts of money to initiative Connect that was used to buy necessary technology. Inderjeet (Public, Jugat) highlighted that his public-colleague Gyaan provided resources to run a patient support group for people with a specific cancer. Initially, this included costs for a venue for the support group and later the support group moved to Gyaan's home and the hospital where Inderjeet and Gyaan were treated sent patients to this support group. In the absence of other financial support, Gyaan was crucial to the continuation of the patient support group:

> **Interviewer: I think it's quite amazing that you've continued...**
>
> Inderjeet: Well indeed, but that's only because of Gyaan. If it had been anybody else it wouldn't have continued…[but]…she's got some money.

Public could not, then, be overlooked as patrons for improvement initiatives and healthcare structures. The ethical implications of this role requires further exploration which is outside of the scope of this study.

4.4 Conclusion

This chapter reported PHCP co-creation was not always routine, necessitating the construction of systems and structures for co-creation. The data demonstrated an interplay between the contexts in which co-creation occurred, the structures created to facilitate PHCP working, and how individuals navigated these spaces. This interplay influenced the value realised by PHCP co-creation for healthcare improvement, and these results addressed the overarching research question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

Connected to this the chapter answers the sub-question:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*

My findings described how the different contexts from which my data was collected influenced how PHCP co-creation manifested. The data from traditional healthcare settings demonstrated how such contexts were seen to structure and socialise both public and HCPs' expected behaviours and roles. This influenced how these individuals were expected to navigate PHCP co-creation initiatives and could prove problematic for public participants who could be perceived to be passive recipients of care, rather than active co-creators of healthcare systems. This emphasises the importance of supportive structures for co-creation seen in the six improvement-focused organisational case studies. This corroborated other research highlighting how improvement organisations facilitate PHCP working[114].

Crucially, this chapter demonstrates that supportive structures were able to optimise PHCP co-creation by enabling people to experience this way of working. I found Wilson et al.'s virtuous cycle for PPI[235] was relevant and could be adapted to present a virtuous cycle of co-creation. In this cycle, the public and HCPs were encouraged to work together to improve healthcare, and therefore experienced or realised some value from co-creation. This then underpinned the importance of PHCP co-creation as a central approach for healthcare improvement, leading some to continue to commit to this way of working. Interestingly, this could also lead HCPs to shift from paternalistic to more collaborative relationships with their patients.

Ramaswamy and colleagues' DART model[82,86] provided a useful explanatory theory to describe how to create successful interactions between the public and HCPs. This model from the value co-creation literature helped uncover how Dialogue, Access, Reflexivity and Transparency was crucial to higher quality interactions between public and HCP co-creators. Combinations of DART facilitated richer co-creation interactions, and therefore experiences, between the public and HCPs. DART therefore, helped manage co-creation and strengthened its experiential nature. This expands Staley and colleagues' assertion that public partners bring experiential knowledge, and that public involvement in research is a learning process[96,106].

This chapter provides the first translation of the DART components for PHCP co-creation for healthcare improvement. It described how Dialogue brought the public and HCPs together, and enabled the public to be part of healthcare improvement. Co-creation enabled both public and HCPs to Access, sometimes previously unidentified information, tools, knowledges and so forth that were crucial to enable more responsive healthcare improvements. Reflexivity enabled PHCP to consider the process of co-creation and improvement but also make adaptations as required. Similarly, Transparency was crucial to enable PHCP to equally and fully engage with each other, especially in healthcare settings. Combining these components enabled the richest PHCP co-creation experiences and increased the likelihood that co-creation realised value.

This chapter tested the applicability of Nambisan and Nambisan's (2013) roles for citizens in public sector co-creation. It found their roles of Explorer, Ideator, Designer, and Diffuser are applicable to PHCP co-creation in healthcare improvement. However, these roles apply to both public *and* HCP co-creators. The individual's influence on healthcare improvement is optimised when public and HCPs work together and co-Explore, co-Ideate, co-Design, and co-Diffuse. This research found additional roles of Advocate, Gatekeeper, Connector and Benefactor were relevant (see Table 8).

Continued overleaf.

Table 8 Roles of co-creators

Roles	Definition
Advocate	Use their positions to encourage and enable co-creation
Gatekeeper	Enable access to individuals & systems, and can regulate when and how co-creation happens
Explorer*	Highlight areas for improvement from experiences of healthcare
Ideator*	Conceptualise potential solutions and suggest avenues to take this forward
Designer*	Design, influence or implement improvements and/or facilitate the delivery of improvement initiatives
Diffuser*	Adopt or diffuse innovations and the scope of healthcare delivery or the improvement initiatives among specific populations
Connector	Actively connect individuals with each other and healthcare systems
Benefactor	Provide resources for improvement initiatives or healthcare delivery

These roles aim to provide co-creators with examples of how they can influence co-creation by providing specific examples of the ways the public and HCPs influenced healthcare improvement. These roles did not always lead to public and HCPs being equally active co-creators. The public's participation, in particular, could be limited by wider structures and existing non-collaborative ways of working.

This research contributes to two broad fields of inquiry. It adds to the PI literature as it describes systems, models, and roles that can optimise PHCP co-creation. The chapter then expands value co-creation literature by using empirical data to translate Ramaswamy and colleagues DART model[82,86] for PHCP co-creation in healthcare improvement. Additionally, it uses this data to test and expand Nambisan and Nambisan's (2013) roles for citizens in public services co-creation[279]. It adds insights from co-creation that occurs for improvement, not profit nor personal benefit.

The next chapter builds on this introduction to experiential systems for co-creation by demonstrating how these enable and constrain PHCP co-creation in four improvement initiatives. The chapter describes the longitudinal co-creation experiences of the public and

HCPs and how these vary over time within different initiatives in the same wider supportive structure. The next part of this thesis will introduce the concept of engagement platforms and provide tangible examples of how they can be designed to optimise PHCP co-creation.

5. Exploring Co-creation Over Time: Public-Healthcare Professional interactions in quality improvement initiatives

"even though sometimes it doesn't seem like we've gone that far, we've still done more than what we set out to do." **Faith, HCP**

Co-creation is an interactional process[82,86,88]. In this thesis, the interactions studied were between the public and HCPs, and between these individuals and the wider healthcare system. The previous chapter described how quality interactions were crucial to personalised, productive co-creation experiences. It described how the Dialogue, Access (to information), Reflexivity and Transparency (DART) model[82,86] could explain high-quality interactions between the public and HCPs and the surrounding system. Chapter 4 demonstrated the combination of supportive, surrounding systems and specific roles for individuals enabled co-creation experiences that shifted practice towards something more collaborative. However, the complex nature of individuals and systems leads to unique and dynamic co-creation experiences that can change over time[82,85]. Chapter 4 demonstrated sometimes these experiences are not always as collaborative and equal as originally desired. Co-creation experiences will be different for different individuals, even if these individuals are surrounded by the same system[89].

This chapter demonstrates these dynamic co-creation experiences through case reports of four improvement initiatives (Woke; Samaaj; Connect; and Jugat) funded and supported by one healthcare improvement organisation (Deep). It presents the interactions that occurred between the public and HCPs in these initiatives over time, and in two cases this data was prospectively collected. This provided in-depth data to further answer the research question:

a. What co-creation interactions occur between the public and HCPs in improvement initiatives?

In particular, the longitudinal insight through the four cases within organisation Deep furthered understanding through more in-depth investigation of the interactions between the public and HCPs. This chapter therefore answers the call to "identify[…] how value co-creation activities and interactions change over time and measur[e] their impact on the relationships between actors within an ecosystem”[274]. This chapter explores similarities and differences in Public-Healthcare Professional (PHCP) interactions and how these change over time in different improvement initiatives supported by the same QI structure. The value co-creation (VCC) theory describes interactions are the “*locus* for the co-creation of value”[82(p19)]. This study, therefore, makes explicit interactions between the public and HCPs, and the wider systems. It aims to shed light on factors that enable high-quality interactions, with the premise that these could increase the likelihood of realising value.

Two aspects of the VCC theory form middle-range, explanatory theories[347] for this chapter. Firstly, it continues the use of DART as the “building blocks” of interactions[82], as introduced in the previous chapter (4.2). Secondly, it introduces Ramaswamy and colleagues’ concept of purposefully designed platforms that facilitate engagement and, therefore, enhance experiences for individuals[85,86]. Examples of these engagement platforms are “meetings, websites… mobile devices… and community spaces”[85]. However, websites or community spaces alone are not enough to facilitate engagement and high-quality interactions[85,86]. To do this, Ramaswamy and Ozcan state engagement platforms need to be assemblages of Artefacts, Processes, Persons, Interfaces (APPI) [86,88]. These four components come together to optimise the capability of the platform to engage individuals[86].

This chapter introduces Ramaswamy and colleagues’ definition of APPI, and redefines the definition using my data for PHCP co-creation in healthcare improvement. It briefly introduces organisation Deep, the healthcare improvement organisation that funded and supported the subsequent four improvement initiatives. This chapter presents the case reports of the four improvement initiatives (Woke, Samaaj, Connect, and Jugat) to describe their use of APPI and how this influenced PHCP interactions over time. Finally, this chapter describes one of the main engagement platforms (collaborative learning events) that organisation Deep created and which all four initiatives experienced.

5.1 Engagement Platforms: Artefacts, Processes, People and Interfaces

The APPI components create platforms that optimise interactions between individuals, and the wider systems and structures of which they are a part[86,88,348]. These platforms enhance individuals’ ability to create value by optimising these interactions. Greenhalgh et al. (2017)

stated strategic partnership boards, Academic Health Science Networks, social media presence are examples of engagement platforms in healthcare[76]. However, this concept of engagement platforms has yet to be empirically applied to describe how they influence PHCP co-creation. As such, each of the four APPI components have been defined for healthcare improvement based on the data collected through this research (Table 9).

Table 9 Definition of APPI from my data

	Definition from Ramaswamy and Ozcan (2018)[88]	**How manifested in the improvement initiatives**
Artefacts	"include physical and digitalized things, including data in the form of numbers, text, pictures, audio, and video"	This included objects, toolkits or digital platforms that were co-created or used in the improvement initiatives, and regularly collected quantitative measurements and qualitative data.
Processes	"include digitized and more conventional business processes of interactions."	A) Healthcare-specific: related to the delivery of patient care, for example processes that enabled medications to be prescribed and delivered to patients in hospital. B) Improvement-related: e.g. use of QI methods (Chapter 7).
Persons	Persons include individuals in their roles as customers, employees, partners, and any other stakeholders."	Various people who form part of improvement initiatives or the wider context that influence the initiative. Included public and HCP who were designers, creators and beneficiaries of the improvements.
Interfaces	"Interfaces include physical and digitalized means by which an entity comes into interaction with another entity."	A) Healthcare-specific interfaces could be the places people came together related to or on the periphery of delivery of care e.g. a hospital ward, hospital reception areas. B) Improvement-related interfaces were spaces where people came together to shape or advance healthcare improvements.

5.2 Co-creation in Practice

This sub-section describes the remit of organisation Deep, and explores how it emphasised and encouraged collaborative approaches for healthcare improvement. This aims to provide insight into the context in which PHCP co-creation in the four improvement initiatives described later in this chapter occurs.

5.2.1 Organisation Deep

Background

Deep won two competitive funding bids (2008-2013; 2014-2018) from a national health research funder that aimed to investigate the translation of existing evidence into practice in healthcare. To realise this aim, the organisation funded and supported a set number of initiatives every year that aimed to improve healthcare across the region. HCPs, occasionally alongside public partners, would propose improvements they wanted to make over 18 month periods. They would apply for funding and support through Deep's formal annual competitive bidding process. Deep would support initiatives to embed systematic approaches to improvement including actively reflecting on, and planning, the implementation and sustainability of improvement through the use of QI methods, and collaborative working and learning.

Deep hypothesised that the use of QI methods provided a systematic method for healthcare improvement. The organisation set up a support system that facilitated the adoption and occasional adaptation of QI methods among the improvement initiatives. These methods, and the collaborative improvement culture created, enabled interactions between the public and HCPs. PHCP working was a core part of organisation Deep from inception and this way of working was positioned as integral to translating and embedding evidence into practice.

5.2.2 Collaborative Working: Improvement as a process with people

Organisation Deep promoted a collaborative approach to QI. This approach was designed to gather and share the knowledge and expertise from all the HCPs who were involved in a patient's care. It aimed to challenge siloed-working by enabling a more complete understanding of all the factors that may influence patient care. This collaborative culture established an expectation that the improvement initiatives would involve HCPs with diverse experiences and specialties, and the public.

Public involvement was a central tenet of organisation Deep. The organisation established a support structure to facilitate collaborative working and learning between the public and HCPs. There was an expectation from the programme that all Deep-funded initiatives would actively involve the public in different ways from the outset:

> “But it’s always… making awareness not only to clinicians but also to the patients and the public and getting them to understand each other, and this is what I like about Deep because they’re bringing [the public and HCPs] together and encouraging change… And by working together you get a much better outcome, not only for the clinicians or for the hospitals or secondary care or primary care, but it’s a much better thing for the patients”
> **Pete, Public**

Organisation Deep therefore positioned PHCP working as normative (5.85.8.2). Key organisational staff, such as senior leads, saw the public as a key part of the improvement process. Additionally, individuals such as the Patient and Public Involvement Lead played a critical role in advocating and supporting improvement initiatives to work with the public. The combination of these highly regarded individuals enabled an organisational culture that promoted and aimed to embed PCHP working. The extent to which, and how, this happened in practice in the improvement initiatives, varied, as the following examples show.

5.3 PHCP co-creation in four improvement initiatives

The following case reports describe PHCP co-creation in four improvement initiatives supported by organisation Deep. Two of these case reports were produced using secondary data (initiatives Woke and Samaaj), and two were produced through prospectively collected data (initiatives Connect and Jugat). Each case report starts by introducing the initiative’s aim, and then presents accounts of PHCP co-creation as it manifested over time. These longitudinal journeys are described using the APPI components to explore the extent to which engagement platforms were a designed part of the initiatives, and their influence of PHCP co-creation. My analysis found each initiative had a dominant APPI component which will be focused on in the case report (Table 10).

Continued overleaf.

Table 10 The four improvement initiatives

Initiatives	**Dates**	**Setting**	**Health condition**	**Main APPI component**	**Retrospective/ Prospective study**
Woke	**July 2010 – 2012**	Acute care	Medicines management	Artefact	Retrospective
Samaaj	**April 2011- Oct 2012**	Community	Endocrine disorder	Processes	Retrospective
Connect	**Oct 2015 - April 2017**	Primary Care and Community	Chronic heart condition	Persons	Prospective
Jugat	**Oct 2015 - April 2017**	Acute care	Cancer	Interfaces	Prospective

5.4 Initiative Woke: A Co-created Artefact

The following case report describes 'Woke', an initiative led by HCPs in a hospital setting who wanted to involve the public to improve prescribing of medications.

5.4.1 Aim

Woke aimed to improve prescribing of medications in older people largely in the hospital setting. The initiative planned to increase reviews of medications, stop inappropriate prescribing, and thereby prevent adverse reactions such as falls. This was partly through the adaptation and implementation of an existing tool that aimed to increase the quantity and improve the quality of medication reviews for older people.

5.4.2 The team and their views about PHCP co-creation

The team were initially a HCP-led initiative that included pharmacists, clinicians specialising in elderly medicine, nurses, hospital-based research staff and so forth. The initiative involved a myriad of people who influenced the patient journey, including those beyond the hospital setting. This included community healthcare teams working to prevent falls and local organisations who commissioned and planned local healthcare services.

The initiative's senior HCPs were motivated and committed to collaborative working with other HCPs and the public. They specifically wanted these people to influence and shape the initiative through their knowledge, experiences, and connections. Such commitment came from a belief that involving end users was crucial to successful implementation:

> "I've always had this ethos that within the NHS we spend so much time and resource in producing initiatives or interventions… that are designed without the end user in mind. And when I say the end user, it doesn't have to be a patient; it could be staff... It's more core project teams or senior management… who create these things and then ask for feedback. And they get a lot of, sometimes, negative feedback and that doesn't surprise me because you didn't ask the question when you started..." **Cezary, HCP**

Woke's senior HCPs were aware of organisation Deep's mandate and assertion that PHCP working was an important part of healthcare improvement, and trusted this assertion. However, they had never worked with public team members before, and had limited experience of involving them to shape services:

> "We're all professionals, trained to do what we do, whereas this, we don't even know what we didn't know… Because, I can remember having a conversation which said, we don't really know what to do in PPI." **Kabeer, HCP**

Individuals in organisation Deep helped Woke to design a focus group where they could engage with people to learn from their experiences of prescribed medications and related processes. This focus group was carried out at the offices of a charity that worked with older people and provided an accessible interface in the community.

Deanna was one of the attendees at this focus group. She was a retired nurse, an occasional patient, and a carer for her child with learning disabilities. Her experiences as a carer enabled her to share details about a document that aimed to aid healthcare experiences of those with learning disabilities:

> "People with [learning] disabilities have got a passport for hospitals with all their details written in it, and it's got medicines written in it… It would be extremely good for elderly people with dementia and whatever… All the information is there." **Deanna, Public**

Other public attendees and the HCP team members felt this document provided a potential solution that could be adapted to support Woke achieve their aim.

5.4.3 The Artefact: a medications document

Deanna and another public team member worked with HCP team members in Woke to evolve a similar artefact for the improvement initiative and used QI methods to shape this artefact. This included embodying the plan-do-study-act (PDSA) cycle approach to iteratively plan and reflect on the co-design and production of the document. In doing so, the public and HCPs established a working partnership strengthened through the tests of change of the document facilitated by the PDSA approach. Both the public and HCP team members felt this approach enabled them to plan adaptations to the document, and reflect on the iterations that emerged. The PDSA approach encouraged dialogue and reflexivity, and enabled transparency as the team members engaged in the co-creation process. These combined factors resulted in a fundamental shift in how the public and HCPs worked together in initiative Woke.

The document was an artefact that provided a tangible example for organisation Deep and initiative Woke of what PHCP co-creation could achieve. The artefact itself appeared to be useful to public and HCPs beyond initiative Woke. However, from the secondary data available it is unclear whether the artefact reduced inappropriate medications and facilitated medications reviews. The artefact was gradually seen as central to Woke's aim despite the fact that it was an unintended, but welcome, side effect of the initiative.

Evidence of the passport being 'of value' was informally gathered and motivated the co-creators to continue working together. One of the public team members, for example, learnt of a woman in the early stages of pregnancy who had had an accident and was sent to the hospital for urgent treatment. The woman was unconscious, but had noted the pregnancy in the passport. This alerted the medical team who avoided giving her treatment that could have threatened the pregnancy.

Public team members would find opportunities to speak about the passport in various public (healthcare and non-healthcare) fora. They would take the artefact with them to different organisations they encountered, and to various regions or countries they visited. Public team members readily crossed geographic or organisational boundaries which proved instrumental in supporting gradual and spontaneous 'spread' of the artefact:

> "…We have not done much more [promotion] and yet I have trusts up and down the country emailing me about the passport. And I think this is down to our patients spreading

> the word and the fact that it's created by patients. I have had emails from the [National Patient Safety Agency] regarding [their] passport, saying, "can we learn from you because we want to involve patients in creating [our] passport?" **Cezary, HCP**

This growing interest attracted new co-creators and evolved the artefact further. For example, a Consultant Geriatrician who heard about the initiative gave their personal time to translate the artefact into an app.

The success of the artefact facilitated active PHCP co-creation. Both the creation and the dissemination of the document provided roles for the PHCP co-creators. This was assisted by Deanna's (Public) amenable nature which led to her being seen as a knowledgeable person "connected all the way up to the [UK health secretary] Lansley" (Cezary, HCP). She became a respected and effective team member in initiative Woke and supported organisation Deep. Another public partner, Hilda, had confidence to speak and connect to people and organisations validating her position in the eyes of her HCP and patient team members. She was well-connected with GP practices and commissioning organisations, and as the initiative evolved became well-known to the HCPs on the relevant sites. Deanna and Hilda became friends and they both developed an ongoing relationship with organisation Deep. They both continued connecting with their HCP colleagues even after the initiative had stopped. Many years later, Deanna mentioned having contacted one of the pharmacists with whom she continued to liaise and discuss her husband's condition.

5.4.4 Implementing PHCP Co-creation

Co-creation was a new way of working for HCPs and most of the public team members in initiative Woke. They worked together in team meetings and therefore needed to learn about each other, their respective ways of working, and how to use this space. This initially led to the HCPs taking a subservient position in these meetings:

> "so when we started with our… team meetings, we were terribly polite and almost deferential to our [public team members], and they got a special chance to talk and even if they went way off what was being discussed, we listened and nodded, and said, "thank you very much", but now that's changed completely. They're just equal members." **Kabeer, HCP**

Some of the HCP team members struggled to work with the public, and there was occasionally tension between these two groups. This was specifically the case with public team members like Bishn who persisted to raise what he saw as potential issues until they were acknowledged or resolved. Other public and HCP team members viewed him as overly-critical and challenging. Co-creation required a shift in working styles and this initially challenged some HCPs commitment to the initiative and working with the public:

> "I don't blame anyone, including myself, sometimes when you get a bit annoyed or flustered. This is a new experience; having three or four patients on your team who are central and sometimes make the decisions is a huge culture change from management doing it and sending it to you to say what you think. It's a huge difference." **Cezary, HCP**

The levels of PHCP co-creation varied. There was significant evidence of PHCP working to co-create and spread the artefact. The success of the artefact and the publicity it received because it was initiated by public team members led to increasing commitment to this arm of the initiative by Woke and organisation Deep. There was, however, more limited public partner influence shaping the initial aim of the initiative:

> "if I think of the actual review form, for example, which we obviously did discuss a little bit [with] patients, but it's very professional-led…and if I look at that, then I'm not saying patients didn't get involved at all, but it was a significantly less so than they did in the passport." **Cezary, HCP**

One of the fundamental challenges to PHCP working throughout the initiative were hospital policies and procedures that aimed to protect patients but limited collaboration with them. The HCPs aimed to access a population that their organisation deemed "vulnerable" and therefore came up against clinical governance and ethics issues. The team found it ironic that they were able to talk to people in the community about their experiences of medications reviews, but not their own patients. Almost a year after the initiative started, Beata the Falls Lead continued to face these issues:

> "I think, probably one of the big frustrations for me was that there was a large user group out there that I could identify that we couldn't access, and that there was a real barrier… Essentially, the clients that I'm involved in on a regular basis, would be the people that we'd want most involved in the project, the people who fall… so we really tried in the

> initial stages to get my organisation on board… so that we can then get the all clear to involve our clients, and that stalled at every step, and it felt very frustrating… You can see how it would benefit the people that we see, but those barriers just didn't seem to be able to come down..." **Beata, HCP**

As time passed, there was a general feeling that the initiative was not achieving everything it had aimed to achieve. This led to questions about whether the initiative spent too much time on the successful, and popular, co-created artefact at the expense of improving medications reviews. HCPs in Woke felt the original aim had been too ambitious. From the data available, the co-created medications document appeared to offer a motivational element that helped the team embed a new way of working and provide tangible evidence of what they had achieved.

5.5 Initiative Samaaj: The importance of processes

The following case report describes 'Samaaj', a coproduced initiative established by public and HCPs that aimed to improve self-management for a chronic condition.

5.5.1 Aim

Initiative Samaaj aimed to improve the management of a chronic condition by working with individuals and communities to increase self-management outside of traditional healthcare settings. This initiative was coproduced by healthcare professionals, the public, and community representatives. A self-management model had been successfully running in another part of London. Samaaj aimed to implement this in two additional London boroughs. The two London boroughs were chosen because of their different demographics, prevalence of the chronic condition, and the potential learning that this could provide. The inner-London borough had longer established relationships between the health and care organisations and the community. In the outer-London borough, the initiative had to establish relationships and work with individuals to engage target communities.

5.5.2 The team

Ruby (Public) had been a carer for a child with the chronic condition. She attended a course run by organisation Deep that aimed to establish effective patient leaders. During this course, Ruby started to think about a form of peer education that could help improve the chronic condition. She continued to evolve a project proposal in her professional Public Health role in the inner-London borough. Ruby and her colleague, Baljeet a Public Health commissioner, co-wrote the project proposal to apply for funding from organisation Deep.

The main project team was formed of people across the two London boroughs. It consisted of people from the communities the initiative was targeting, Public Health staff, and a national organisation for the chronic condition. There was a community outreach worker in the outer-London borough who aimed to engage specific communities.

A core team met regularly and drove the initiative. One third of this team were community representatives who were service users, carer representatives, or members of target communities. These individuals would all take on different roles. For example, Assata (Public) engaged with the processes being used to drive the initiative and led on inputting the data that was being captured. She was seen as a valued and crucial member of the core team. Maynard (Public) focused on co-designing and implementing the various processes that the initiative established within the community. He would visit other places or organisations to learn from similar initiatives. Additionally, two individuals from the national organisation became core team members, and one was co-located with the project team. They became instrumental in sharing the learning between the initiative and the national charity.

5.5.3 Improving self-management processes through champions, mentors, and educators

Initiative Samaaj provided useful insight into the importance of processes to engage people through specific interfaces, as described below.

The initiative trained individuals as champions, mentors, and educators to embed processes that support and improve self-management. These individuals would provide peer support and education to those with the chronic condition, adapting a community health worker model (6.2.3). This model trains and supports members of communities to provide basic healthcare provision, support or information within their community[44]. In their adaptation of this model, Samaaj established roles for Champions, Mentors, and Educators. Champions went into communities and raised awareness, Mentors provided one-to-one support to those with the condition, and Educators delivered educational programmes.

Champions

Champions were unpaid individuals located in the geographic communities the initiative was targeting. They were provided with training to support them to increase awareness of the chronic condition, especially among people that may be high risk or not engage with traditional healthcare settings. The Champions came from diverse backgrounds and were representative of the boroughs in which they lived.

The Champions would hold events and through these engaged thousands of people across the two boroughs in which the initiative was being implemented. Initiative Samaaj gave the Champions the freedom to hold any type of event they felt would work to engage the communities they were targeting. The public and HCP team members mentioned it was difficult to understand how effective the different types of events were, but there were frequent examples that these interfaces were achieving tangible value:

> "I come across patients that were diagnosed with diabetes for 10-20 years but they were not sure about what are the things they can eat or shouldn't eat. They always had the idea "Oh I shouldn't eat any sugar, any fruit". Even yesterday, I had an event with the Tamil community and I was told that they never ever had bananas and mangos… since being diagnosed with diabetes. So these are the myths attached to this condition being changed as a result of these sorts of events." **Tariq, Public**

Mentors

Mentors provided one-to-one educational and emotional support to improve self-management among those with the chronic condition. This was a new model that initiative Samaaj created and implemented, and was continually evolving. The learning from the Champions and Educators processes was shared at the team's regular reviews of how the processes were working in practice, and fed into developing the Mentors. For example, learning from recruiting Champions highlighted the importance of a structured recruitment process because "if we let loose cannons off, there will be serious consequences for us" (Maynard, Public).

The team found Champions and Educators were initially easier to recruit than Mentors. This may have been because of the uncertainty about how the Mentors model would work, and the national organisation working alongside the initiative were particularly interested in its development. As the initiative evolved, it became apparent that this model could achieve more by being connected to primary care settings. The team, including the community representatives who were already Champions, felt this would connect Mentors to those who would benefit most from this model. Testing this approach proved fruitful, and provided a new way of embedding this process:

> "…One woman [the mentor] worked with had diabetes with very poor control for 5-6 years. The [General Practitioner] referred her to the mentor who has seen her 6 times. The patient claims she has never before understood what diabetes is; what the medicine is for and how to take it; how what she eats affects her diabetes; and that taking exercise matters. The mentor saw her at a women's exercise class at the centre last week, and she said she was feeling much better and happy to be doing something." **Baljeet**, **HCP**

Educators

Peer Educators were paid to teach people with the chronic condition through more formal educational sessions. The Educators would co-lead on a structured training programme, alongside a nurse, or a dietician. The structured training programme offered people with the chronic condition a specific number of educational sessions at set times and days. The team found it relatively easy to find and train people who wanted to be Educators. However, it was difficult to encourage people to attend the structured courses even though it became apparent that there was a need:

> Peer educator: 5 active peer educators, have been able to double the teaching. Very satisfying to deliver, [although attendees are] travelling at different speeds. Main problem- the number of people attending the courses needs to be increased. Not economical currently because not enough people come. 3-10 currently attend. 12-15 would be better.
>
> **Maynard (Public) monitoring review notes**

5.5.4 The Artefact: Measurement to improve the processes

Initiative Samaaj were keen to be able to provide evidence that they had made a difference. This desire was part of the team's longer-term strategy to build a strong case for re-funding or recommissioning amidst uncertainty about this created through changing organisational structures. The initiative worked closely with organisation Deep to create useful measures to regularly monitor and assess the initiative's processes, outputs, and outcomes. This was an iterative activity of testing and refining the measures until the team felt they were useful and could facilitate easy collection of appropriate data. The team felt the process of creating measures in this way led to something useful for public and HCP team members.

The measures were added to a web-based reporting tool that enabled the team to input, view, and access the data. Organisation Deep's staff continued to support both HCP and public team members to use the tool. The team highlighted the importance of this supportive human interaction for successful uptake and continued use of the process:

> "… it wouldn't have worked without [QI programme staff]. It needed the human inter[action].. they've been great actually… because if you just had the tool on its own, it's scary, but they've been excellent in helping us through it." **Ruby, Public**

Assata (Public) took on responsibility for inputting the data into the system even though she did not have a computer because she saw value in the process. Initiative Samaaj specifically commissioned organisation Deep to create the web-based reporting tool and support them to continue using it to collect data beyond the original project timeline.

5.5.5 Value of the initiative?

The PHCP partners viewed the co-creation process in Samaaj as being of value. This was particularly the case for the inner-borough part of the initiative where the established community relationships led to more successfully embedding processes to realise the initiative aim. PHCP partners felt the processes they embedded had enabled them to connect with communities and individuals who were not accessing traditional healthcare settings. The public partners, in particular, were able to support these communities and individuals to manage their chronic condition. Some clinical HCPs saw value in this process and engaged with the public partners. For example, this process enabled GPs to connect patients who were having difficulties managing their chronic condition to a support system and people who could assist. This support system worked because it was created and led by people who lived with the same chronic condition or shared characteristics with patients, such as language, culture or religion.

Some clinical HCPs, who either specialised in this chronic condition or provided primary care, did not always see the value of initiative Samaaj. They challenged the competency of public partners to support others with the chronic condition. Other HCPs felt the initiative was only of value if it evidenced improved health outcomes for people with the chronic condition, and there was limited evidence of this during Samaaj's funded period. Interestingly, recent reports have highlighted that the Champions and the Mentors models are still being sustained many years after Samaaj started, perhaps indicating that this coproduced initiative is realising some value.

5.6 Initiative Connect: Person-driven improvement

The following case report describes initiative Connect which aimed to improve screening for a specific condition through GP surgeries and the community setting. This initiative provided a useful example of the importance of people driving engagement and enhancing this through artefacts, processes, and interfaces.

5.6.1 Aim

Initiative Connect aimed to improve detection of a heartbeat irregularity in older people across one London borough. This irregularity is easily treatable but could lead to a stroke if it remained undiagnosed. This could cause poor quality of life for patients and create high costs for healthcare systems. Initiative Connect aimed to screen target populations in General Practice and the community setting, and support GPs to initiate treatment as required. The initiative provided GP surgeries across the borough with heart rate monitors approximately the size of a credit card and smart phones to which the monitors would attach. These devices would connect to a monitoring app that enabled people (healthcare professionals or the public) to check heart rates for irregular heart rhythms. It provided a small, accessible, mobile method to screen for the condition within 30 secs without the patient having to go to a hospital setting. The GP practices across the borough varied in their uptake and actual use of the heart rate monitor and the app.

5.6.2 The team

The core team initially consisted of Nima, a consultant, Rita, a GP, Mary, a specialist nurse, and Pete, a public team member. These four team members had been part of a borough-wide clinical network for two to three years prior to them starting this initiative. The four team members worked well together with respect and trust, perhaps because they formed their relationships slowly over this time. A project manager and a community nurse were recruited as the initiative progressed.

Nima, a consultant, was based in the hospital-setting, had specialist knowledge of the condition, and how it was managed through existing healthcare delivery. She was respected and seen as "everyone's favourite cardiologist" (Rita, HCP) by patients and HCPs. She was adept at marketing the initiative in a way that ensured it received support or buy-in.

Pete, the public team member had lived with the condition for a number of years. He had strong networks with national charities related to the condition, in the community setting, and among healthcare professionals. He was a retired business-owner and was one of Nima's patients. They worked as colleagues in this initiative, but at times Pete would stay behind after Connect team meetings to ask Nima questions as his clinician. Pete had worked with other improvement initiatives that Deep had funded and supported, and completed the organisation's improvement fellowship. This resulted in him having the greatest knowledge of QI and organisation Deep among the team, and this was useful in shaping the initial funding application:

> "Well, Nima made the application. Then I said to Nima, as I'd just finished my fellowship, I could give her advice on how that application should look, and we sat down and went through the application using certain magic words." **Pete, Public**

He saw patient and public awareness as his main role in this initiative, including raising awareness of the condition, the risks, and screening individuals. Other team members often referred to him as their "patient representative", and although he mentioned to me that he was not a representative, he never challenged them.

Rita was part of the local commissioning group and a partner in a local GP practice. She was, therefore, a conduit between the initiative team, the GPs across the borough, and the commissioning structures, and "has a very powerful voice within [primary care]" (Pete, Public). Rita had specialist knowledge about the condition, its treatment, and the national guidelines.

Mary, the specialist nurse, was more unclear about her role in the initiative. Initially, she felt her role would come when the community arm of the initiative started. Mary's nature as a doer led her to feel conflicted by her peripheral, almost observer-like status while the initiative focused on primary care. She maintained contact with the team, and managed the community nurse. However, she started to disengage from the initiative and focus on her main role in the hospital.

The team recruited Anita as a project manager because the core HCP team were too busy delivering patient care to manage the project's growing workload. Anita's responsibilities were to drive the project and manage the roll out of the screening programme to GP surgeries in the borough, including providing training and monitoring uptake. Initially, she struggled to adjust to the already established initiative team. She felt the dynamics in Connect created an environment which assumed a level of knowledge about what needed to happen that she did not possess.

The community nurse was the last person to join the initiative but very quickly integrated and became an active team member. She got on well with the rest of the team, the QI programme staff, and the wider hospital staff. Soon after she came into the role she started an improvement fellowship with organisation Deep and, interestingly, referred to herself as a QI nurse. She worked closely with Pete because her role included educating and training volunteers to run screening sessions, establishing clinics for screening, and engaging with patients not receiving treatment.

While this group of individuals was largely cohesive, there were occasional examples of conflict, specifically between Anita (HCP) and Pete (Public), manifesting in the team meetings. Anita was not used to working with public team members. The fact that Pete was unpaid and there was no clear directive of his role may have been the cause of some of Anita's apparent insolence. Anita would not acknowledge Pete and she could be quite rude to him, including not communicating with him about key issues that related to both their roles:

Continued overleaf.

Connect team meeting

[National advocacy charity] will provide some community volunteers to train on a day in January. This meant a meeting arranged between Anita and Pete next week does not need to happen. Pete was perturbed saying "I'd appreciate it if I'm told when things get changed." Anita seemed to brush him off, saying "well, I never committed to that [meeting]". She didn't seem to understand the wider issue. It took Nima (consultant) coming in to appease the situation saying, "Pete you are absolutely right, and normally such updates would be fed back at the Friday meeting, but absolutely there needs to be feed back".

Later in the same meeting:
Pete was speaking of a time he did some health training for a person and someone told this person and her boss that he should be paid. They ignored this advice and didn't pay Pete. Anita looked at me, raised her eyebrows, and smirked.

Field Notes: 9/12/2016

This conflict was, however, largely ignored by the initiative, remaining an undercurrent throughout the project.

5.6.3 Regular collaborative working

The team met weekly to discuss and drive forward the improvement initiative, mostly in Nima's office at the hospital. These meetings included staff from organisation Deep, and any other individuals relevant to what the team was doing at that point in time. There would be a hive of activity in the room mirroring the rapid momentum in the initiative's work. These meetings became crucial to update everyone and plan next steps because the initiative would progress very rapidly with lots changing within a week. The momentum of the initiative and things happening rapidly engaged people, and encouraged them to be part of the project:

> "I think that's where we've been lucky because things have moved and you're getting results, and my experience of sitting on other projects is things can get a little bit stagnant.

> People start dropping off. Whereas, the momentum of this is what's really driven us and that's where I think we've been lucky." **Pete, Public**

Pete's knowledge of the borough, and his strong networks with HCPs led to him engaging a GP who had been resistant to the initiative. Therefore, his position and connections were an advantage that brought benefit to the initiative.

The regular collaborative working enabled all the team members to engage in reflexivity and dialogue to advance the initiative's aim. For example, the initiative needed to add a template onto the GP system for patient records. This template would tell the initiative how many people had been screened and who had tested positive for the condition. However, there were difficulties adding this template to the system resulting in inaccurate data being logged. This data therefore needed to be re-inputted and Pete offered to take on this responsibility, much to Rita's (HCP) relief:

Connect team meeting:

Rita says "oh that would be such a help because I was dreading going to the GPs and asking them to go back and add in those patients because there would be uproar". Anita (HCP) adds "They wouldn't do it".

Field Notes 2/9/2016

Over the coming weeks, Anita (HCP) and Pete (Public) tried repeatedly to get access to the system so Pete could re-input the data. They encountered problems because Pete was not a formal employee, even though he had formally volunteered at the hospital for a number of years. This issue remained unresolved leaving Anita to input the retrospective data.

5.6.4 The role of people for screening

Additionally, the team aimed to increase and improve screening outside of GP surgeries and set up screening in community settings and screening-training events to achieve this aim. These would take place at the hospital, supermarkets, libraries, community centres, places of worship, and with voluntary sector organisations. This was a successful and acclaimed part of the initiative providing the team and organisation Deep with a visible example of the use of a high-tech device to screen target populations. Pete (Public) was a key player in this arm of the project as he had long-standing links with the community and had experience of speaking about his condition. He, therefore, provided the HCP team members with a way of connecting with people who could have had the condition and may have anxieties about this:

> "[Pete and I] would go out for the screening events together… He would do the "being an [heart condition] patient talk", so that was great. Pete has been great, supportive for the patients as well as for the team… He gave us a connection to connect with the patient and connect with the public, and even with the volunteers..." **Sarah, HCP**

In one surgery, a junior doctor who had a good relationship with Nima, the consultant, had taken on the screening. However, Rita's (GP) own practice was only an average performer in terms of screening. Therefore, the variation in screening appeared to be influenced by factors beyond relationships and interactions between humans. An instant messaging group was set up on the smart phones that enabled the GPs to share ECGs for second opinions from Nima. Again, uptake of this service varied. Ultimately, for some GP practices the artefact appeared to provide too many technological issues.

5.6.5 The artefact facilitating PHCP co-creation

Pete (Public) had privately purchased his own heart monitoring device and frequently showed this to HCPs in a variety of settings, including conferences or regional meetings. His knowledge and experience of the artefact positioned him as an expert who could provide advice:

Connect team meeting

Nima (HCP), Pete, and staff from three GP practices were present. One GP said they were having difficulties with patients pressing the [heart rate monitoring] device too hard, thereby turning off phone. [They] wondered if the phone could be on table. Pete mentions that is how they use it for screening in the hospital or community, so it is possible.

Field Notes: 15/03/2016

The artefact and the community screening arm of the initiative provided strong evidence of Pete bringing together knowledge and people. He was frequently aware of issues with uptake or use of the device that the rest of the team did not know. By bringing this knowledge back to the team, Pete was able to facilitate further support to struggling GP practices and increase the likelihood that they engaged with the artefact. It was however, difficult to evidence whether this feedback made a difference to outcomes and led to increased screening.

Collaborative Learning Event Time: 13:35

I walk in and Pete (Public) and Rita (HCP) are sat next to one another. Pete is telling Rita about a GP practice where they've had an issue with using the [heart rate monitor] device. One GP had an issue with the device, didn’t want to use it, and wanted to send the person for an ECG instead. Pete had said to them that they could talk to Rita. She gets more details about the practice and she says she is happy to talk to them as the data has shown [that surgery is] one of the areas that have low screening levels. What is more interesting to me as an observer of their interaction is the mutual levels of respect that seem to exist for what they have both brought to this conversation/encounter.

Field Notes: 03/11/2016

5.6.6 The success of the initiative

Initiative Connect was generally deemed a success by the immediate team, organisation Deep, and academic and healthcare networks across the region. Soon after the initiative started, screening for the chronic condition became a national priority. The team were, therefore, doing something that was required, and doing it relatively well by screening more people than had previously been screened in the borough. They received national awards and were asked to disseminate their learning nationally. Initiative Connect was therefore, deemed to be a success. Much of this perception of success came from the numbers of people they screened and the process they embedded for screening in primary care.

There was not the same drive to work with the wider public (beyond Pete) as there were in the other initiatives described in this chapter. The levels of regular collaborative working with the public veered between cursory and well-intentioned, depending on which team members initiated these efforts, and their views of this way of working. General consensus, initiated by

Nima (HCP), was that the public would be involved in the community arm of the initiative. While this happened, and the public did actively screen in the community setting, it seemed to become a subsidiary aim. Individuals such as Rita (HCP) actively sought opportunities to work with the public "because they know best", but others in the team did not hold this view, including Pete (Public). This view, combined with the fact that the initiative was doing "well enough" seemed to limit the potential of working with the public, and what this way of working ultimately realised.

5.7 Initiative Jugat: Interfaces for improvement

The following case report describes 'Jugat', a HCP-led initiative that focused on improvements for people with a specific cancer.

5.7.1 Aim

The aim of initiative Jugat was not as clear as the other initiatives described in this chapter. The people connected to the initiative had different understandings of its aim, and the aim itself evolved over the duration of the project. Mandeep, a surgeon, led the initiative's initial funding application that was submitted to organisation Deep. The aim stated in this application was to enhance recovery for a specific cancer through early mobilisation of patients post-surgery. Around the time Mandeep submitted his funding application, Chanan, a specialist nurse, had applied for funding from the hospital charity for a project aiming to prepare patients for their impending surgery. Chanan had also applied to be part of Deep's improvement fellowship to support her with this project. Mandeep and Chanan had senior positions at the same hospital where both had worked for many years, but were unaware of each other's applications or proposed projects. Organisation Deep highlighted their respective proposals to each other and suggested these were combined:

> "… [Deep has] brought the [initiatives] together… in a way that they should be. But had it not have been for a little bit of luck along the way, and organisation Deep, and the charity's grant, I think we'd probably both still be working in our own little way… Because I would have wanted to achieve my objective and Mandeep wanted to achieve his, and we would have probably seen each other as rivals, rather than just say, "OK, let's work together on these things"…" **Chanan, HCP**

During the initiative, some of the HCPs and the public who joined the team later, continued to refer to the primary aim as preparing patients for surgery. This was specifically the case for public and HCPs actively working alongside Chanan on her arm of the initiative, possibly related to it being a clearly articulated project. Additionally, this arm became more visible to public and HCPs, who were co-creating and using the related e-health platform, and this visibility reinforced this work as Jugat's primary purpose.

Jugat aimed to collaborate in two ways to realise their aim. Firstly, they aimed to enhance recovery for patients and share learning of how this could be achieved across three hospitals. There was visible resistance from the outset from one of the hospitals, and another initially disengaged, leaving the hospital that Mandeep and Chanan worked in as Jugat's main site. Mandeep brought together a multidisciplinary team of approximately ten people, including physiotherapists, dieticians, surgeons, and nurses to achieve Jugat's aim.

Secondly, Jugat were committed to working with the public to shape what early mobilisation post-surgery would look like. Mandeep mentioned one of his patients had the original idea that post-surgery recovery goals should be negotiated with each patient. Building on this, the team aimed to challenge norms that positioned patients as "passive recipients [who] follow instructions [and planned to] make them active participants in order to improve adherence to [enhanced recovery programme] elements" (Jugat Funding Application). These collaborative efforts were new ways of working for the initiative's team. There was a general sense from the various HCP team members that the initiative exemplified collaborative working and decision-making that was not "normal practice":

> I ask "Have you been involved in this type of project before?", Dorothy (dietician) answers "No, never, and it's been great, a real team effort with everyone able to influence decisions, not like normal practice where you have some doctors or surgeons making all the decisions".

Organisation Deep provided the HCP team with support to enable them to engage and work with the public. This support initially came through Chanan's improvement fellowship, and later, through specifically designed interfaces to bring the public and HCPs together.

5.7.2 Interfaces: Spaces for PHCP co-creation

Organisation Deep worked with initiative Jugat to design specific spaces for PHCP co-creation. The main spaces took the form of three separate events that took place over seven months. These events aimed to bring together the public and HCPs to share experiences that could inform efforts to enhance recovery through early mobilisation, and co-design Chanan's e-Health platform. These spaces and events were co-designed, mainly by Mandeep, Chanan, and Deep's PI Lead and a QI facilitator. Chanan was seen as a major proponent of working with the public and, therefore, critical in initiating these interfaces:

> "I think one of my advantages was working with Chanan because [she's] such a strong patient advocate and she… has always challenged me in terms of getting rid of the very paternalistic, very surgeon-like attitude towards patients." **Mandeep, HCP**

The events were an interface where staff at organisation Deep, initiative Jugat, patients/carers, and occasionally App designers would all come together. There were between five and eleven patients and carers present at each event, with attendance declining in the later events. These spaces were social and functional. Individuals from different backgrounds came together in social spaces and their interactions centred on experiences of health and care, and they carried out tasks and activities focused on improvement. The interfaces enabled dialogue, access to information, and reflexivity, and broke down barriers between professional roles and human experiences:

> "I think what we're really trying to do is actively challenge those stereotypes [assigned by people's roles in healthcare] and break down those barriers. Because I'm a patient, I've been to hospital on many occasions. I'm also a carer, I've had to look after people who are unwell… They're people, we're all people together, and I think, I hope that's what those kind of workshops really nurture." **Chanan, HCP**

The events brought HCPs together with a diverse group of public with whom they had not worked before. These interfaces, therefore, created structured and facilitated spaces that enabled HCPs to invite the public to shape the initiative and related work. This supported Jugat's senior leads to model new ways of working with the public to inform healthcare design and delivery, which was noticed by junior staff:

Dorothy (Dietician), Akari (clinical research fellow) and I are sat around a table at one of the events: “Things have changed. If you said, 5 years ago, that a [specialty removed] surgeon would be engaging patients like this, we would have laughed.” says Akari to Dorothy. “Really?” asks Dorothy, Akari nods. Dorothy says, “well I guess surgeons are a different group”.

Field Notes 20/10/2016

These events were purposefully designed to take place in impartial community venues. There was a view that this would enable full participation from the public who may have had negative experiences in the hospital setting. Public partners did attend these neutral spaces, however, observations highlighted the distance between these spaces and HCPs’ clinical settings made it more difficult for them to access. HCPs in Jugat would frequently mention restrictions on their time: “I need time when I don’t see patients, I don’t do clinics, I just sit down and work on this [initiative]” (Louise, HCP). Therefore, travelling to locations away from their hospital meant they would arrive late, or leave early, depending on their clinical commitments.

Inderjeet and Neena were two crucial public partners who were part of the initiative from the beginning, and had a significant presence at these events. Inderjeet was retired and 7 years post-surgery. This latter fact received audible gasps of awe when he mentioned it at the collaborative spaces because of the high mortality rate for this condition. Inderjeet appeared to be a confident person who was comfortable working with HCPs and was involved in improving cancer services across the UK. The HCPs would introduce Inderjeet as “our patient advisor”, and he would be one of the first to speak at events. As the initiative progressed, Inderjeet’s national involvement work expanded and his commitment to this project reduced. Neena had been treated by Mandeep and Chanan, and worked full-time. She had never before had interest in actively improving her wider community or healthcare settings. At one of her clinical appointments, Chanan asked Neena to write down the different experiences she had had throughout her treatment. Neena was then invited to the attend Jugat’s first collaborative meeting that aimed to conceptualise the initiative’s aims and potential solutions. She was part of the initiative in a variety of ways for the duration, including being part of a video highlighting rehabilitation techniques.

More public partners became part of the initiative through these collaborative spaces. These were often Mandeep and Chanan’s former patients. This could bring a very present patient-HCP dynamic that challenged Mandeep and Chanan’s view that the patients were partners. However, the HCPs would also interact with the patients socially, for example, to raise funds for the hospital. Interestingly, the team tended not to invite the public co-creators to other collaborative spaces related to the initiative, including organisation Deep-initiated meetings or learning events. When questioned about why they did not invite the public team members, the HCPs mentioned they were hesitant to ask these patients for too much time. This hesitancy was influenced by the HCPs knowledge of people’s diagnoses, treatment, and ongoing conditions that impacted these people’s quality of life and increased the likelihood of an early death:

> What I found particular interesting were Chanan’s comments towards the end of the review about how patients could continue to be involved in the project. She mentioned that she is hesitant to involve them because “we are buying them time, rather than curing the cancer… I get worried that we’re going to pull them away, if we put too much on the poor guy who should be spending it with his [family] or whatever…”
>
> I’ve not thought of this before, and the knowledge that clinicians have about patients’ conditions, especially life-threatening ones, could influence how comfortable or able they feel to involve patients in improvement. Ultimately, I suggested they ask the patients, and I think communicating and being honest with them can overcome this. But it highlights why clinicians dealing with patients with particular conditions, and specifically the knowledge that clinicians can have about those conditions, can influence or potentially create barriers to involving patients.
>
> **Field Notes 12/12/2016**

5.7.3 The Artefact: An e-Health platform

Initiative Jugat provided a useful example of interfaces, and the co-design of an artefact further demonstrated how the public and HCP worked together warranting further exploration.

Chanan had engaged public who suggested an e-Health platform would be useful to help people prepare for surgery. This was an online or app-based platform that would provide patients and carers with information to improve their preparedness before and after surgery. Chanan realised patient involvement and engagement could provide useful information to improve people's preparedness:

> "But a lot of people… are saying… "I didn't have the information"… It's that richness of knowledge that comes through that we need to think, "OK, let's just challenge ourselves here". We know we gave them those sessions but why is it that they're not actually able to process it and what can we do to facilitate that process?" **Chanan, HCP**

Public and HCPs in Jugat tested the usability and functionality of this platform during the events, and suggested changes based on how they would use it. The public team members generally felt the platform had potential and was of value. They would reflect on their own experiences of care to influence the information the platform would provide to future patients.

However, the extent to which patients/carers could influence the e-Health platform in practice was limited as it built on Chanan's previous work. The public involved in the inception of the idea were different from those involved in shaping the actual development. Additionally, the platform was at an advanced stage and prototypes already existed. This limited the public partners' influence:

> Mandeep (HCP) plays the video in the e-Health platform and asks everyone to make notes on the video [of whether] it is ok. He says this after the video ended, as though it is an afterthought, or he is seeking validation for something already set.
>
> **Field Notes 20/10/2016**

The platform was new to both HCPs and the public which further limited people's ability to shape its design. The public expected the HCPs to be familiar with the platform and would ask them questions if they struggled with it. The HCPs, in turn, had to work out the solution or ask the platform developers. The platform then facilitated, but also hindered, interactions among the public partners, and between them and the HCPs. The older members at the sessions struggled to engage independently, while the younger patients or carers tended to be more confident and familiar with the technology. This confidence and familiarity enabled them to better interact with the platform and the other people present. When the public struggled with the technology, the quality of their interactions with the other attendees reduced and were led by those more confident with digital technology:

> This is a very tech focused workshop which works fine for Neena (Public), and Jujhaar (Public) who is taking hold of a tablet and working his way through it and has the group around him. But [it's] quite alienating for Neil (Public) whose involvement is limited as I can see he struggles with the tablet. He ends up holding it and Aimee (HCP) goes over to him and takes him through it; with her pressing all the buttons.
>
> Interestingly, the healthcare professionals not sat at one of the patient tables go and join Neena and Jujhaar's table, where [there is a rich] level of engagement with the tablet... At this table, the tablet works well to get people involved and interacting [with each other and the device]. In comparison, Neil and Aimee are just engaging with each other, whereas Jujhaar's comfort with tablets means he is driving his own and others involvement [in the device and the initiative].
>
> **Field Notes 20/10/2016**

After exploring the e-Health platform, Inderjeet in particular challenged its promotion as the solution. He stated this particular health condition tends to have an older demographic who may not be as comfortable with the use of technology. He went on to relay an experience which showed the effectiveness of using simple methods to convey information to the public:

Inderjeet (Public) mentioned Mandeep (HCP) explained the operation and provided information by using a biro and drawing on paper. There is an audible sound of agreement from others in the room who had also experienced this and found it useful.

It is, therefore, ironic that this project uses e-Health innovation when simplicity works.

Field Notes 24/03/2016

5.7.4 PHCP co-creation as an exemplar of success

As the project progressed, these spaces and events, and working with the public, were seen as exemplars of success by the initiative's team. Their way of working with the public had been recognised by organisation Deep and at a national award ceremony. This level of success led to a virtuous cycle of co-creation[235] (4.2.1; Figure 12) where experiencing such value motivated the team, and encouraged them to continue to involve patients:

> "Our other…achievements… I must say, as we are very proud of our patient engagement events, and we've been working very closely with patients in developing the e-Health Platform. They've been involved in all the workshops to do with the definitions of the elements, the prioritisation of the elements, and the [driver] diagram. They've contributed a lot to our project." **Mandeep, HCP**

Some public attendees similarly found these spaces useful, motivating, and worth being part of:

I ask Inderjeet how he found [the event], and he says "Good, very productive."
I ask "what do you mean?" He replies, "well, more productive than some of the other groups I go to. It is a good group of patients".

Field Notes 20/10/2016

However, these interfaces took resources that initiative Jugat's team would not always have, as the money and support for the events came partly from organisation Deep. Additionally, the public and HCPs needed to commit considerable amounts of time that took them away from patient care or their daily activities. The HCPs were particularly concerned about this for public partners since people with this particular condition did not always have the best quality of life. While the interfaces provided an effective and generative way of successfully bringing together the public and HCPs, they did not provide a sustainable solution for long term co-creation:

> "we need to rethink the patient engagement event and how we move forward with patient engagement per se, because they're quite labour intensive. Well they take a lot of organisation. We don't have a huge pool of patients that we can always draw from, and that's something that Mandeep and I have just talked about… how we really maintain the momentum in terms of keeping patients involved?" **Chanan, HCP**

5.8 Engagement platforms for PHCP co-creation in healthcare improvement

This section provides an overview of the engagement platforms that existed in the four improvement initiatives previously discussed. It then goes on to describe the collaborative learning events that organisation Deep ran that were the only platforms with which all four improvement initiatives engaged. As such, these particular engagement platforms offer useful insight of how the initiatives engaged with these, and the potential or challenge these brought for PHCP co-creation.

5.8.1 Engagement platforms demonstrated by the four case studies

The previous sections demonstrated platforms for engagement existed throughout the four case studies of the improvement initiatives, and Artefacts, Processes, Persons, and Interfaces (APPI)[86] were to some extent components of these (Table 11).

Table 11: APPI demonstrated across the four improvement initiatives

	Woke	**Samaaj**	**Connect**	**Jugat**
Improvement focus	Medicines management	Endocrine disorder	Chronic heart condition	Cancer
Main engagement platforms for PHCP co-creation	Focus group; Team meetings	Team meetings; Community spaces where learning sessions took place	Team meetings; Hospital entrances or communal spaces; Community spaces where screening took place	Purposefully designed spaces to work with the public
Artefacts	Medications document	Collection of data, and using a web-based tool to collate and report it	Heart rate monitor and Smart phones	E-learning platform
Processes	QI methods, including collaborative working and PDSA cycles	Processes to support and improve peer-led self-management	Screening processes; QI methods	Facilitation for PHCP co-creation; QI methods
Persons	HCP core team, with public team members joining later	Coproduced by the public and HCPs; Engaged specific communities	Many HCPs and one public on the core team; engaged with communities through screening	HCPs core team, with occasional public co-creators
Interfaces	Deep organised collaborative learning events; Various healthcare spaces	Community spaces	Community spaces; Hospital entrance areas	Community spaces used for PHCP co-creation

5.8.2 Collaborative Learning Events as Engagement Platforms

This sub-section introduces the three-monthly collaborative learning events that organisation Deep designed and ran. These fit Ramaswamy and Ozcan's definition of purposefully designed engagement platforms but the organisation did not use this theory to shape them. It is important to study these engagement platforms as all Deep's improvement initiatives had access to them, thereby providing learning from somewhat comparable contexts and situations. Crucially, the platforms themselves could offer learning for other people who want to create these for public and HCPs working together in healthcare improvement. These collaborative learning events will be described and their APPI components will be briefly explained. I will then assess how successfully they engaged initiatives Woke, Samaaj, Connect and Jugat.

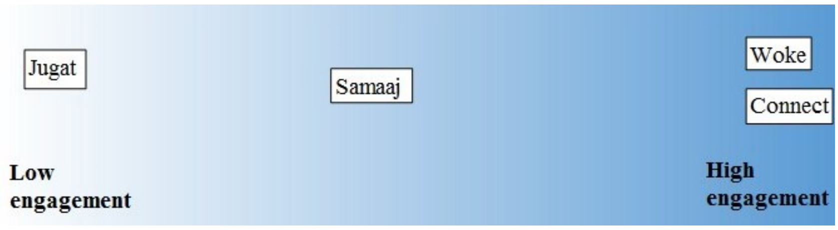
The collaborative learning events were day-long platforms that supported improvement initiatives and fellows that came under the umbrella of organisation Deep, and the wider healthcare community across the region (**people**). Each day had a specific focus related to core aspects of healthcare improvement, for example, engaging the public or sustaining improvements. The day was designed to motivate the attendees and provide them with the skills to improve healthcare.

The events often took place in medical colleges that were located outside of healthcare delivery organisations (**interfaces**). Organisation Deep designed these interfaces to enable different methods of engagement, for example, through lectures, interactive workshop areas, or marketplaces. The marketplaces would introduce the attendees to toolkits for QI methods that people could take away, show interactive displays, or play films of patient journeys (**artefacts**).

The day would be split into different sessions that participants could attend where they learned about, or applied, processes to help them make improvements in healthcare. This included through the guided use of QI methods, including those organisation Deep recommended, or learning about **processes** that other improvement initiatives may have created, such as health screening **processes**.

These platforms were used by Woke (5.4), Samaaj (5.5), Connect (5.6) and Jugat (5.7) and my analysis demonstrated the initiatives' engagement with the platforms varied (Figure 15). High engagement with the platform meant the initiatives would bring public and HCP team members, and regularly attend. Low engagement meant the initiatives would rarely attend or would not invite all team members (Fieldnotes 3/11/2016).

Figure 15 Initiatives' engagement with the learning events



High engagement with the platforms enabled these spaces to be used to support and critique initiative's PHCP co-creation activities. For example, at one event, a person working for a national organisation that aimed to involve patients in research was present and provided useful challenge to initiative Connect about their plans for PHCP co-creation (Fieldnotes: 7/7/2016).

My analysis found two interrelated characteristics enabled the collaborative learning events to successfully engage people; their continuity and evolvability. The continuity of the events enabled public team members from initiative Woke to continuing engaging with the platforms for many years after the improvement initiative ceased. The evolvability was a nuanced process that will now be described further.

5.8.3 Improving engagement by evolving the learning events

The collaborative learning events continued to evolve throughout and beyond the duration of initiatives Woke (5.4), Samaaj (5.5), Connect (5.6), and Jugat (5.7). However, the evolution of these events during the lifecycle of initiative Samaaj provides a particularly interesting illustration of this process, and the impact this had on PHCP co-creation.

At the beginning of Samaaj, the majority of the team felt these events impeded rather than facilitated co-creation. They felt these events perpetuated hierarchies and were aimed at initiatives from clinical settings. The public team members, in particular, felt the event agendas were dominated by QI methods:

> "I went to three events and beyond that I was choking to death and couldn't possibly sit through another one. Absolutely dreadful. Self-congratulatory. They were entirely taken up by QI processes…" **Maynard, Public**

Ongoing dialogue between Samaaj and organisation Deep provided useful opportunity for reflexivity that enabled consideration about how the learning spaces could evolve. Organisation Deep worked to establish more interactive sessions, strengthened peer-learning elements, and considered the accessibility of spaces at the events.

While some public team members continued to disengage with the events, others felt these changes made the platforms more useful, and in line with the initiative's collaborative culture:

> "the second learning…[event] I went to is the one we had last week. I actually did find it collaborative for the first time… We had… more time to talk as a team. [There was peer

> learning]… so the people… came to our group, we talked a bit about our [project]… we asked them about theirs, and I heard what they were doing and what the issues were with involving children, and how they were doing this..." **Baljeet, HCP**

Assata (Public) reported the events, and specifically the peer-learning aspects, supported her to explore new ways of implementing aspects of the initiative. She stated "…It's been absolutely amazing, and the different ways that people have approached things and I've thought… "oh I might try that" and it's expanded the way I've been able to deliver things". She was able to learn through interactions with the HCPs from other improvement initiatives that attended the events. Interestingly, Assata was able to learn from a challenging interaction with HCPs at the event, and apply this to her difficult relationship with her doctor. This resulted in a more collaborative partnership between Assata and her doctor:

> "One of the things I did learn from [the collaborative learning events] is that doctors and patients speak entirely different languages. So I was able to go back to my doctor and say "actually, you don't make any sense when you talk to me like that. What I want you to do is speak to me as a person, and not as a patient"… this has made a lot of difference between me and my doctor… It has made him think in an entirely different way… And that came out of listening to a really awful comment from one of the groups of clinicians [at the learning event] and they said "oh no you get the patients involved because they are cheap""
>
> **Assata, Public**

5.8.4 The potential of engagement platforms to optimise PHCP co-creation

Ramaswamy and Ozcan (2014) provided a useful theory to describe engagement platforms that are constructed to optimise the interactions between people and systems[86]. This theory describes that designing spaces and approaches to facilitate co-creation is a considered and purposeful construction, rather than an accidental process. These platforms are, therefore, an example of "informal theory [that] is always at work in improvement, [but that] practitioners are often not aware of it or do not make it explicit"[126]. Thus, it was useful to test the potential of Artefacts, Persons, Processes and Interfaces as necessary components that could make explicit how interactions between the public and HCPs are facilitated. APPI described how multiple, interrelated components can work in sync to optimise PHCP co-creation in the healthcare improvement initaitives that were part of this study. Therefore, Ramaswamy and

Ozcan's work on engagement platforms provides a useful framework to help prospectively shape spaces for public and HCPs working together for service change.

The four cases demonstrate that engagement platforms are used, in various ways, and the relationship to the initiative's overarching aim influences how and why these are designed. In the cases described, these platforms were not always purposefully designed which could have impacted their effectiveness for engagement, or may highlight shortcomings in directly applying the APPI model for PHCP co-creation. Initiatives Woke, Samaaj, and Jugat purposefully-created spaces to facilitate PHCP co-creation. Initiative Connect created these spaces to achieve the overarching aim of engaging people to improve screening. Additionally, all initiatives engaged with the platform organisation Deep purposefully designed.

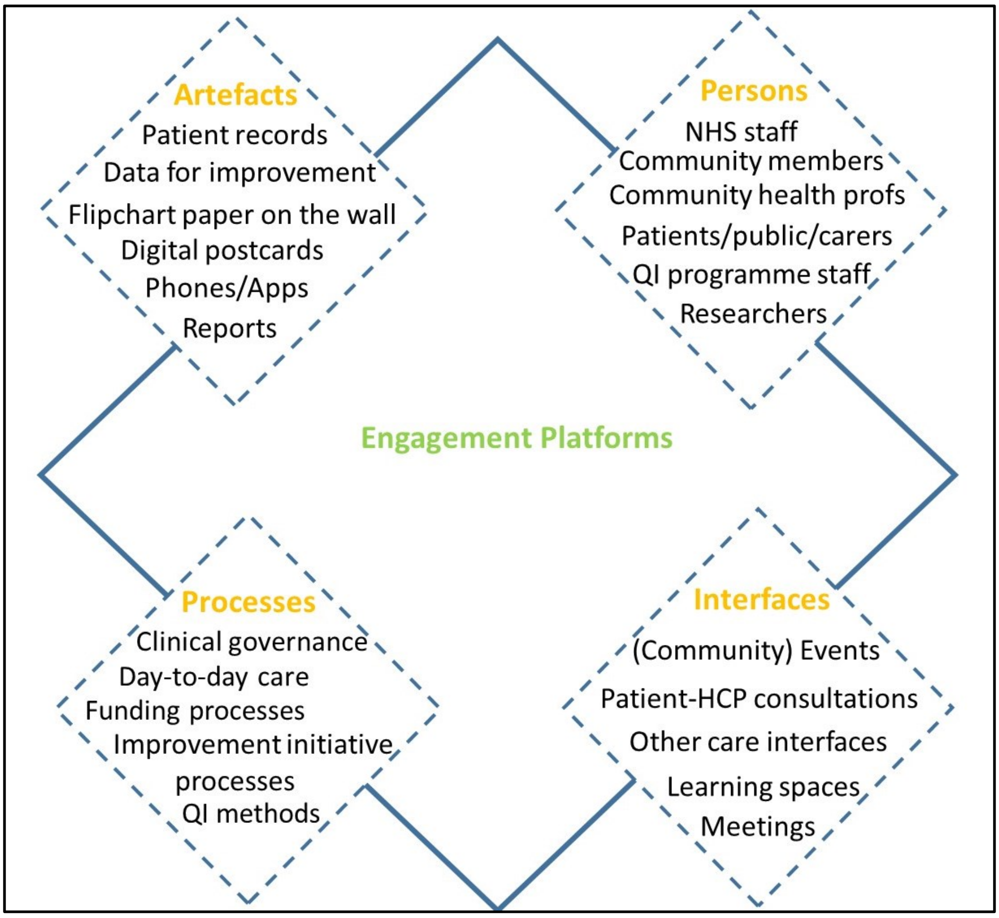
Individuals from organisation Deep supported initiatives Woke and Jugat to design the platforms through which they worked with the public. These same individuals from Deep also facilitated the events or spaces that were created. This demonstrated an underpinning process that optimised how the platforms enabled PHCP co-creation and this should be more explicitly explored. Research could investigate the extent to which such engagement platforms could optimise PHCP co-creation without this specific and responsive facilitation.

Initiatives Woke, Samaaj, and Jugat demonstrated the significance of the temporal nature of these platforms. In all three of these cases, PHCP co-creation happened over time and the platforms that aimed to engage people evolved as relationships changed. This flexibility and responsiveness influenced how the public and HCPs worked together, and how they accessed and shaped spaces for healthcare improvement.

This analysis has provided empirically-grounded definitions of the various APPI components for PHCP co-creation in healthcare improvement, from the different case studies described in this chapter (Figure 16).

Continued overleaf.

Figure 16 Examples of APPI from my data (Diagram adapted from Ramaswamy and Ozcan 2018, with permission)



It is interesting to note that the APPI components did not exist in equilibrium in any of these platforms, and there was evidence of dominant components in each initiative (5.8.1). This may be because people designing these platforms did not know about Ramaswamy and Ozcan's theory[86]. However, it could equally be that not all APPI components are crucial for co-creation in this setting, or that PHCP interactions are complex and influenced in more nuanced ways. The extent to which APPI is applicable, therefore, does need further research. This includes understanding the public and HCP's views about how useful this model could be in helping them proactively shape engagement platforms in health and care settings.

5.9 Conclusion

This chapter described PHCP co-creation in four improvement initiatives within one healthcare improvement organisation. In doing so, it answered the question:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*

This analysis demonstrates that even though PHCP working was a central tenet in organisation Deep, the extent to which this way of working was realised in practice, including in the four improvement initiatives, varied.

Samaaj provided the strongest example of PHCP working throughout the initiative. Public and HCP team members were seen as equals in this coproduced initiative that aimed to improve self-management through peer-led education. There was evidence that the partnerships between the public and HCPs were productive, and enabled the initiative to achieve its aim. Public and HCP team members used their skills and networks to navigate both healthcare and community settings. Furthermore, initiative Samaaj demonstrated a Dialogue, Access, Reflexivity and Transparency-rich (DART) culture that facilitated higher-quality interactions between public and HCP team members. This led to spaces where the team members could have open and honest dialogue that shaped iterative planning and improvement of the initiative's processes. Dialogue and reflexivity between initiative Samaaj and organisation Deep enabled them to work through tension and ensure it became generative. This led to sharing views and providing information that could support organisation Deep's iterations of the regular learning events.

Senior HCPs in initiatives Woke and Jugat were similarly motivated and committed to work with the public, but neither initiative knew how to make this happen. Both initiatives were acute-based. Woke aimed to improve prescribing among older people, and Jugat aimed to improve preparation for surgery and early mobilisation post-surgery for people with a specific cancer. Organisation Deep provided critical support to manage and facilitate PHCP co-creation in both initiatives, and this as one of the most successful aspects of Woke and Jugat. This resulted in the co-creation of the medications artefact in Woke, which spread beyond the initiative's organisational boundaries. PHCP co-creation led to a less tangible output in initiative Jugat, but was still seen as successful because it exemplified a way of working deemed desirable in surrounding healthcare structures. However, PHCP co-creation was limited to specific aspects of the initiative, and there were other arms of the improvement work where this way of working was not evident.

These findings highlight an interesting relationship between what is deemed success, and co-creation. Co-creation was deemed a success in initiatives Woke, Samaaj, and Jugat, internally by PHCP team members and externally by organisation Deep or through national recognition. The core teams of initiatives Woke and Jugat felt they achieved more limited success in other parts of their work and neither fully realised their original aims. PHCP co-creation became the showcase for both initiatives and an exemplar of success. Conversely, PHCP working was a core process in initiative Samaaj, therefore, underpinning this way of working as a crucial part of achieving the initiative's aim. The fact that Samaaj embedded a way of working that was desirable in surrounding healthcare structures deemed the initiative a success. It became an exemplar improvement initiative for organisation Deep, and other health and related organisations, who were excited to see PHCP coproduction in action.

Initiative Connect was deemed to be a success irrespective of their PHCP co-creation. The team eventually produced measurable results to show they had increased screening for the condition in the specific borough. In doing so, they demonstrated they were one of the leaders among those tackling these nationally-agreed priorities. Alongside this, the initiative had a public team member, and established links with the community to advance the screening. PHCP working was, therefore, functional but there was little evidence to demonstrate the core team deemed it as necessary as evidenced in the other three examples. This did not detract from how favourably the initiative was viewed across the region, and the less meaningful co-creation could have been masked because of this success. In other words, there was not enough reason to do anything differently in any parts of the initiative, including having more meaningful PHCP working.

The results demonstrated the potential issues in seeing meaningful and tokenistic co-creation as respective sides of a linear spectrum. Initiative Connect echoed Martin et al.'s (2017) findings of PHCP working that was functional and could not be said to be tokenistic[63]. Specific HCPs in Connect did try to work with the public in more meaningful ways to shape the initiative, but such working was less impactful than in the other initiatives. Similarly, in initiatives Woke and Jugat there were examples of more and less meaningful co-creation. Individual personality traits could lead some HCPs to commit to working with the public, more than other HCPs. Variations between more and less meaningful could also relate to a specific part of the improvement initiative. Some parts being deemed the focus for PHCP co-creation while other parts were seen as largely for HCPs. Co-creation practices from these examples did not fit on a linear spectrum between tokenistic and meaningful then, but rather exemplified a nuanced journey between being more or less meaningful.

Finally, there were examples throughout the case descriptions of engagement platforms facilitating interactions between the public and HCPs, and between these individuals and the surrounding systems. Different Artefacts, Processes, Persons and Interfaces[86,88] were present in all initiatives and provided a useful understanding of platforms to optimise PHCP working. Crucially, it was the combination of these platforms with Dialogue, Access, Reflexivity and Transparency[82,86] between co-creators that helped overcome tension and improve the quality of interactions between public and HCPs. Therefore, APPI and DART formed useful middle-range theories to explain PHCP co-creation. Nevertheless, the APPI components were not equally evident in the platforms created by the initiatives for PHCP co-creation. Applying APPI as an explanatory framework provides useful insight into how these platforms could be designed to optimise PHCP co-creation. However, this analysis has not been able to address questions about whether more effective engagement platforms have all the APPI components, and whether these components are equally important to optimise PHCP co-creation.

The collaborative learning events designed by organisation Deep showed engagement platforms were not enough on their own, to initiate high-quality interactions. Each initiative engaged with these platforms very differently, questioning the extent to which one platform can suit all situations. This research highlighted the importance of these engagement platforms evolving to be responsive to need. Therefore, prospective research exploring the extent to which engagement platforms and DART can formatively facilitate or impede PHCP co-creation would be useful. Such research could investigate the possibilities or limitations of APPI and DART to shape PHCP co-creation in healthcare improvement, but also in other settings.

The next chapter uses all the data collected and presents what can be achieved through PHCP co-creation. It describes the value of PHCP co-creation, in terms of the benefits and costs, for individuals, organisations, and society. In doing so, it sheds light on whether the efforts to form engagement platforms and optimise PHCP co-creation is worth it.

6. The value of co-creation for healthcare improvement

> **Interviewer:** "Do you think they know why they're involving patients?"
>
> **Rohinton (Public):** "At a conceptual level yes, I think the NHS has got a huge commitment to public involvement because they know that bringing the public with them is actually a key issue… but I think that making it work so it actually adds value is probably not entirely resolved."

The value of co-creation and how this value should be assessed are contested. Perceptions vary about whether this way of working achieves value as the quote above highlights, even among public and HCP co-creators. This is partly a result of variation in the practice of co-creation potentially resulting in divergent consequences and outputs, and also relates to how people view and position this way of working. Some people may see public-HCP (PHCP) co-creation as a democratic right that should always be practised regardless of what it achieves[349]. But other people say a stronger evidence base can persuade people to enact this way of working[42] and improve its practice[349]. Importantly, this evidence base can build a case for co-creation at a time where there is increasing competition for finite resources[69,70], and thereby need to assess its impact.

This chapter aims to address the third gap presented in Chapter 2 relating to the ongoing debate about how best to assess the impact of PHCP partnerships. Assessing this impact has been deemed necessary[350] and difficult[23]. This section answers McKevitt et al.'s (2018) call to "investigat[e] how value is produced—and for whom—through involvement" and to test whether this "might offer a way of rethinking impact assessment in involvement"[77]. This chapter presents a prospective exploration of value of PHCP partnerships. It uses all the data collected to address the following sub-question:

b. *What value is achieved through PHCP co-creation, and why is it deemed value?*

In doing so, it provides background for the overarching research question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

Exploring the value of PHCP co-creation can be deemed contentious. It can be said to further position this way of working within a neoliberal agenda that focuses on privatisation, competition, and a reduction of state responsibility[60,181]. It shifts the right of the public to shape healthcare systems towards an individual responsibility, and reduces the obligation of the state[60,181,205]. In turn, this emphasises value in an economic sense and defines this concept as what is achieved for the money that is spent[67]. This may seem at odds with the democratic right of the public to participate in both their personal and wider healthcare planning.

Research to date provides examples and ideas of how patients, the public and communities could be involved in creating value[39,71,80,81,351]. This includes self-management, peer-led models of care, patients teaching healthcare professionals, and ultimately the co-production of healthcare[39,71,80,81,351]. While there has been some focus on the economic assessment of value[68,352], others challenge the use of this approach for public involvement[249] and advocate widening this definition[80,81]. This is partly because of the iterative, dynamic, and unique nature of co-creation[249], as described in the previous chapter through the longitudinal studies of four unique and dynamic improvement initiatives. These four journeys demonstrated that what was deemed value, and by whom, varied throughout those improvement initiatives. A challenge remains of how the value of co-creation can be assessed.

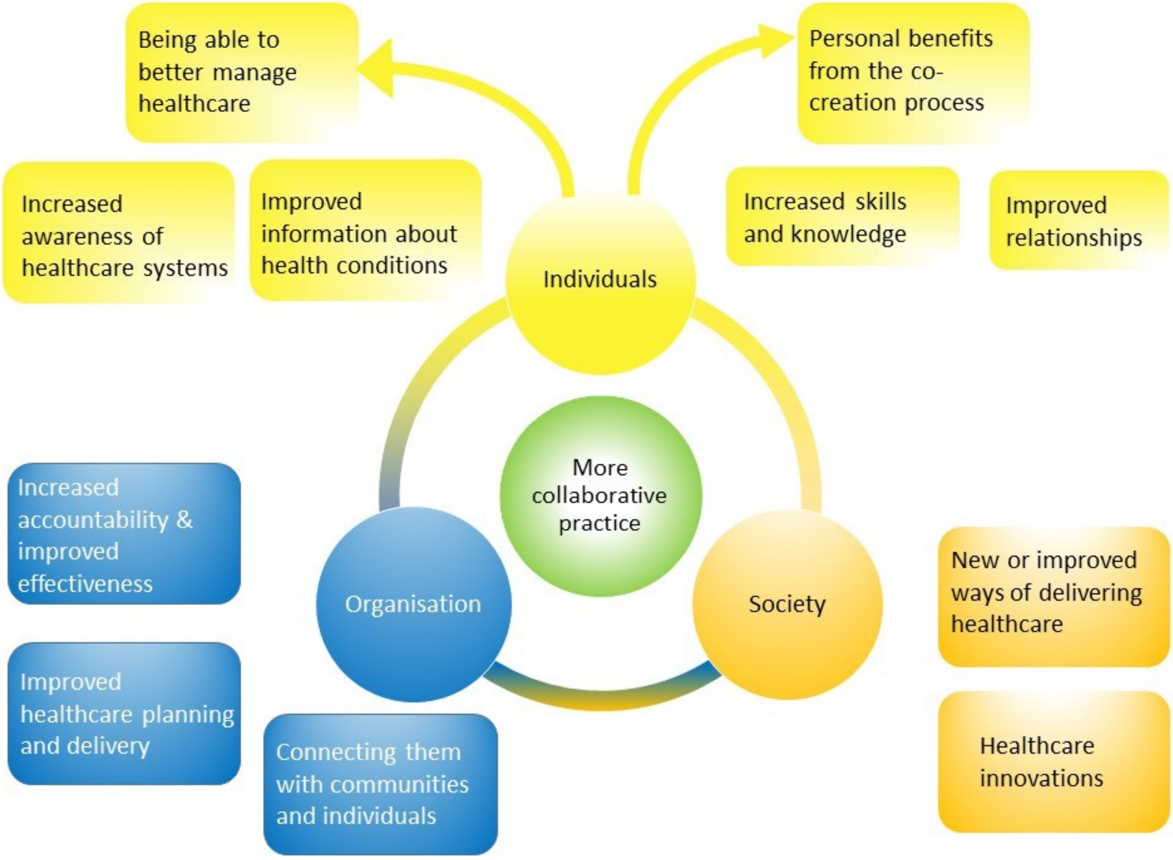
This chapter explores the value of PHCP co-creation. While not providing an economic assessment of value, it borrows the terms that underpin the monetary definition. This section assesses the benefits and costs of this PHCP co-creation using all the data collected in this study. It makes this assessment from what people directly and indirectly said about benefits or costs, and observations of co-creation in practice. It further assesses the factors that influence why co-creation is deemed to be of, or realise, value.

This chapter is structured to firstly outline the benefits realised by PHCP co-creation for individuals, organisations and society. Secondly, it describes the factors that influences whether the process or output of co-creation is deemed value. Finally, the chapter explores the (largely) non-economic costs of co-creation.

6.1 The value of co-creation

The data analysed suggests significant evidence that PHCP co-creation realise value for individuals, organisations, and society more broadly (Figure 17). Examples include more accessible patient information, improving improvement initiatives, or creating new or improved ways of delivering healthcare. The value co-created was dependent on the individuals involved, the context, and what was deemed value. This is consistent with literature that argues value is unique and determined by what is meaningful to individuals[82,110]. I found value was dynamic and fluid and not contained at the individual, organisational, or societal levels. Thus, value realised for individuals could lead to value for organisations or society, and vice versa. For example, individuals being able to better manage their health could support efficient healthcare usage, and new ways of delivering healthcare could, in turn, help these individuals better access healthcare.

Figure 17: The value of co-creation



6.1.1 Realising value for individuals

Co-creation created value for individuals by enabling them to better manage healthcare and providing them with personal benefits realised through the co-creation process.

a. Being able to manage healthcare better

The data demonstrated that participating in co-creation helped some public and HCPs better manage health and wellbeing. This was largely because of the increased awareness of health conditions and systems. Section 7.2.1 describes how the public partners' experiences of healthcare could help them uncover the realities of healthcare planning and delivery. This section, therefore, describes the co-creation process and the impact of improved information about the nature and management of health conditions.

Improved information about health conditions

PHCP co-creation provided a process to support reflection and adaptation of information about health conditions. This information was "vital to any sort of dialogue between clinicians and patients, and… likely to lead to better outcomes" (Salima, Public). The data demonstrated public and HCPs co-created useful and responsive information about health conditions, in formats that were deemed helpful. This included written information to enable individuals to actively engage in their own care. In a small number of cases, co-creation persuaded HCPs to make healthcare processes explicit to patients/carers, thus providing useful information on how to navigate the system to support better management of specific conditions. For example, Nana (HCP) described an initiative where patients mentioned they did not fully understand the radiography process that they were going to encounter as part of their treatment. Nana, therefore, worked with patients to design open evenings where they would see the equipment, have tours of the process, and hear from past patients.

Public participants were able to better manage their health conditions through improved awareness of their conditions gained through the co-creation process. Ajeet (HCP) shared an example where he initiated a paediatric asthma club with two young brothers with poorly controlled asthma. The brothers were accountable for managing finances and given significant responsibility for the club. Through these roles they gained confidence as individuals, and their asthma improved through better self-management. The club also enabled other children to benefit from enhanced engagement with, and management of, the condition:

> "…giving them that kind of responsibility and that authority made a huge difference, not just to their asthma… but actually to them as individuals… And a spinoff of… the asthma workshops, was that a lot of other poorly controlled asthmatic children attended those workshops and benefited from the interaction of not just the boys but the asthma nurses who were also involved." **Ajeet, HCP**

Some examples showed public participation to improve healthcare systems led to improved healthcare outcomes for these individuals. Additionally, there was a relationship between PHCP co-creation improving systems, and improving health outcomes for public co-creators and among others individuals with similar conditions.

b. Personal benefits from the co-creation process

The main benefits for individuals from the co-creation process were increased skills and knowledge and improved relationships. While the former relates to public partners, the latter largely influences HCP practice and both will be discussed below.

Increased skills and knowledge

Sub-sections 4.1.6, 6.2.1, and 7.1.2 provide examples of the new skills that co-creators developed and how their confidence grew because of co-creation. This section explores how the skills and knowledge participants felt they would gain were a mechanism to realise broader aspirations. Some people felt their participation, linked to these new skills and experiences could for example result in improved opportunities for longer-term employment. Ezra (Public) stated his participation in organisation Ekta offered "a chance to come off benefits" and provide opportunities to develop a career. It led to him being paid "really well…[and] what they pay us…shows that they value us" (Ezra, Public). However, these longer-term employment opportunities did not always materialise for some of the public partners. Shavo (Public) was an unpaid volunteer in initiative Samaaj (5.5) who thought his commitment would result in paid employment. He was disappointed that this did not happen despite him being one of the most active team members in the initiative, and he needed to explore other avenues to paid employment.

Improved relationships

The act of working together over time facilitated a different, or better, relationship between some PHCP co-creators. Some HCP co-creators gained better awareness of the public as they worked alongside them, and were more likely to see a person rather than a patient. HCPs learned more about how the public lived with specific conditions and the impact of treatment on their daily lives. This awareness influenced how these HCPs worked with the public as partners to improve healthcare systems. This could lead to more collaborative healthcare practice (sub-section 6.2.1). Specifically, it changed how HCPs dealt with individual patient consultations. Some HCPs embedded co-creation in their clinical interactions with patients:

> "I'm fortunate to [still] be in…General Practice one day a week, and the practice that I work in is deeply interested in how people experience care, and hence [are] involved in the decision making and service change etc." **Dave, HCP**

These HCPs highlighted that they embedded greater shared decision-making which in turn reduced waste since people "ask[ed] for fewer investigations… so less tests, less interventions" (Ajeet, HCP).

6.1.2 Realising value for organisations

Co-creation realised value for organisations through increased accountability and improved effectiveness, and improved healthcare planning and delivery as described in this sub-section. Additionally, co-creation realised value by connecting organisations with target communities and individuals as described in sub-sections 4.3.6 and 6.2.3.

a. Increased accountability and Improved effectiveness

My findings demonstrated public co-creators were more likely than HCPs to work across organisations or geographic regions, corroborating findings from Renedo and Marston (2014)[37]. This, together with their position as outsiders to the organisation, led some people to view public co-creators as having more influence than HCP employed within healthcare or QI structures. Both public and HCP participants felt these factors enabled the public to provide challenge, thereby holding individuals, initiatives, organisations, and programmes to account:

> " …When you do have a patient in the room…and they have found how difficult the system can be, they can effectively tell the clinician, "this is what you should do". And

> it's quite powerful, because it's almost like pulling rank, as it were… We don't really have any control over clinicians, and especially the people at the top of their field… I think that's a great value…of a patient being in the room and influencing the direction of a project." **Igor, non-clinical HCP**

A few interview participants mentioned co-creation being a core part of the organisational approach. In these instances, public co-creators permeated throughout the organisational governance structures, and had opportunities and influence over more effective running of the organisations (4.1.6;4.2.3;5.2.1;7.1.2).

Part of the public influence over organisational accountability and effectiveness came from them bringing together different people and healthcare organisations with varied priorities. For example, some public co-creators were conduits between patients/carers and multiple healthcare organisations. This helped these co-creators critique organisational running and priorities. They were able to verify organisations' planned and delivered healthcare based on actual, not assumed, need:

> "In a way I'm beefing up the team by not being part of the system really… I think that's probably quite useful, and again you're not blinded by technology because that's not what you're interested in. You're looking at how things affect the patient and so you do have a slightly different aspect. And you're [going into organisations and] actually talking to patients which surprisingly the nurses don't always do." **Amrit, Public**

Some HCPs mentioned facing added pressure to deliver what they needed to, or said, they would, because of the physical presence of public co-creators. This would strengthen these HCPs' commitment and ensure they prioritised active co-creation and healthcare improvement in spite of their other potentially time-consuming obligations:

> "…we're really, really busy and if something was cancelled at the last minute everybody would think, "oh thank God for that, I've got a day now to try and sort this out"… But if you've got a group of patients coming… you cannot cancel, you have to deliver on it. You have to make sure that everything is completely right… and…get everything just as it should be before the event." **Chanan, HCP**

Public presence would then provide increased accountability compared with a traditionally HCP-led environment and influenced how HCPs behaved. Additionally, the physical presence of the public and HCPs working together was seen as a contributing factor in dissipating tension between different HCPs. HCPs were more mindful of their behaviour in a shared public space:

> "But one of the things I was invited to do… was to go to a GPs' training day on cancer. And we were just chatting over lunch with one of the people who'd organised it, and she said to me, "do you know they behave a lot better when there are members of the public here"… that quite amused me..." **Rohinton, Public**

The additional pressure and accountability provided by the presence of the public prompted HCPs to be actively engaged participants in healthcare planning at the organisational level. Experiencing co-creation encouraged HCPs to continue working collaboratively to facilitate healthcare improvement and planning (sub-section 4.2.1).

b. Improved healthcare planning and delivery

PHCP co-creation realised value for healthcare planning and delivery specifically through improvement initiatives and was the strongest, most prevalent theme from my analysis. Co-creation shaped improvement initiatives and public partners specifically could be instrumental in making these initiatives actually deliver healthcare improvement. This has been covered throughout this thesis (4.1.6; 4.2.3; 4.2.4;5.4;5.5), and, therefore, the significant findings are recapped.

PHCP co-creation provided strategic advantage for some improvement initiatives by evidencing a way of working that was desired or required. Healthcare improvement was facilitated by creating space and time that physically brought together the public and HCPs and established relationships and collaborative working between them. The multiple perspectives enabled individuals to find solutions from divergent experiences rather than solely from healthcare settings where people may think the same. This led to tangible improvements to structures, systems, and process (4.2.4;5;7.2). Public partners as individuals or groups were seen as powerful, influential, and able to use their presence to bring status to the initiatives in which they participated. This corroborates McKevitt et al.'s (2018) concept of substantiation meaning the public's physical presence "ma[de] an idea physically present"[77] and verifies Armstrong et al.'s (2013) "technology of persuasion [where the public are] a means of influencing opinion and debate". My findings showed public co-creators were able to garner wider organisational support for initiatives:

> "…it can be such a massive thing when you've got patients involved because it can give validation to the project. It can get board sign off, board funding… if [public] champion a project it means that people that might not have been interested before are suddenly… Patient voices…are much louder than your average clinical…professional." **Mia, HCP**

There was a perception among HCP participants that public partners sometimes held more power in healthcare and improvement funding structures.

Public partners used their presence and experiences as powerful influencers to garner support and resources from healthcare and related organisations. This provided tangible benefits, including funding that facilitated further improvement work:

> "So we wanted to get some leaflets… to show the parents what actually is involved in the blood tests and [mum] went with us to… one of the local charities to help bid for the service, and she talked about her experience but also those of other parents and again those powerful stories helped us win those final funding bids" **Ajeet, HCP**

There were also examples of the public supporting HCPs as colleagues and facilitating healthcare delivery. Public partners in initiative Samaaj (5.5) provided "services free [of cost] to the individual [GP] practices" (Maynard, Public).These GPs would connect the public co-creators to people who were struggling with their specific chronic condition, and the co-creators would in turn support these people to better self-manage. This increased awareness of the initiative to external HCPs and patients/carers who accessed the public co-creators for self-management advice. Additionally, public co-creators accomplished core tasks by providing access to support for self-management for people with the condition.

6.1.3 Realising value for society

Co-creation realised value for society through healthcare innovations that related to new or improved ways of delivering healthcare. A summary of new and improved ways of delivering healthcare are discussed in this section with examples contained within other chapters of this thesis (for example 4.1.6; 6.2.3). Healthcare innovations are discussed in section 6.2.2.

a. New or improved ways of delivering healthcare

PHCP co-creation challenged entrenched mindsets and normative behaviours that led to healthcare systems being designed as they always had. Co-creation brought together different perspectives on what the issues were with current healthcare planning and delivery, and the different individuals could bring alternative solutions to tackle them. The synthesis of perspectives contributed to new ways of planning healthcare delivery that reflected what mattered to public partners and patients/carers:

> “one of the guys was [an] insulin dependent diabetic and… someone was saying, “oh this is going to be really difficult, gosh I’m not sure we can do this” and he was like, “Tell me why you can’t do that, because that’s exactly what I want that will get me where I need to be”. And then people then started saying, “well, yes actually, why could we not do it? Can we think differently? Let’s think out of the box…”” **Dolores, HCP**

Co-creation encouraged more responsive healthcare planning and delivery. Specifically, it enabled people to consider radically different solutions to respond to the issues arising from healthcare not being planned with the end users in mind. This consideration led to solutions such as the Community Health Workers (CHW) model being implemented (sub-section 6.2.3).

6.2 Why is something deemed value

Reflections: Who defines the value that is achieved from co-creation? That is where this starts to become complex. Ultimately, it is defined by those involved, those who are somewhat involved, through either supporting the initiative, funding, championing, promoting etcetera. This includes funding bodies, supporting [QI] programmes, healthcare organisations – including hospitals, commissioning groups, GP surgeries etcetera, as well as wider [potential] beneficiaries. But inevitably, the definition of value as determined by such a wide and varied group is itself, wide and varied, and therefore it is difficult to achieve and/or demonstrate value has been achieved through the co-creation process.

Fieldnotes, 27/4/2017

Why something is deemed value is influenced by who is making the assessment and how the value manifests, as shown by the data presented in this sub-section. Thus, there were differences in what co-creators saw as the value, what was realised through co-creation and what others external to this process saw as value.

People who were part of the co-creation process were more likely to appreciate 'experiential value'. That is, the value realised for, or added by, individuals through the co-creation process, or for people through their subsequent experiences of receiving, shaping or delivering healthcare. However, this was often not widely visible and could be deemed anecdotal. This latter point was emphasised by a clinical consultant who challenged the value of Samaaj's initiative during a presentation of my research findings. The data showed the initiative's team felt they had made a difference and realised experiential value (5.5). However, this consultant felt Samaaj had not been able to evidence impact of health outcomes in the way to which they were accustomed. This example shows it is more difficult to demonstrate experiential value to those external to the co-creation process.

'Tangible value' was more likely to be visible and demonstrable to those who were not part of the co-creation process because this was quantifiable data or tangible products. Such data or products were seen to have inherent value in specific contexts or by certain people. For example, the co-creation of an app by initiative Jugat was seen as having value by those who were not part of the co-creation process. The tangible nature of the app, and a wider healthcare context which promoted the use of technologies, may have facilitated this perception. Initiative Jugat was, therefore, seen by some external people as having realised value, despite the fact that the initiative had not proved the app was of use.

There were examples of improvement initiatives that managed to bridge both tangible and experiential value and sit in the 'intersection'. These examples described tangible products or noticeable processes, which provided improved and/or personalised experiences that realised 'experiential value'. These three forms of value (experiential, tangible, and the intersection) are described in more detail in sub-sections 6.2.1-6.2.3.

6.2.1 Experiential Value

Experiential value was realised by the public and HCPs through experiences of the co-creation process and of health and care.

Public co-creators were motivated by opportunities to develop, for example, through social interactions and intellectual challenges. Co-creation provided them with an opportunity to give back to healthcare and the healthcare professionals who had treated them for specific conditions. These co-creators wanted to do this in a meaningful way that 'added value' to the process or to healthcare systems. This meant “as a result of a contribution I make, something changes and that one feels that either at the time, or later, that that’s a change for the better” (Rohinton, Public). Seeing or believing they added value motivated the public to continue to work with HCPs in healthcare improvement initiatives. Co-creation provided intellectual challenge while demonstrating the healthcare system at work, helping the public learn about the intricacies and underlying processes of healthcare planning. Additionally, public participants could grow and develop new skills and confidences through the co-creation opportunities and interactions (b). The process could push public co-creators out of their comfort zone and provided new opportunities. Krisztina (HCP) noted “their confidence [grew], and…they were doing things they didn’t think they could ever do”.

HCPs stated their healthcare practice became more patient/carer-focused because of working with the public as partners. The relationship between public and HCP co-creators could change over time and HCPs were more likely to see a person rather than a patient. These HCPs learned more about how the public lived with specific conditions and the impact of treatment on their daily lives. This influenced how these HCPs worked with the public as partners to improve healthcare systems. It further led to some HCPs initiating more collaborative consultations with patients/carers, including through better involving them in their own care:

> “by working with patients as equal partners… my consultation style is a lot less paternalistic than it used to be… I’m very much a kind of coaching clinician where I will speak to the parent or the child and…talk through the options and… they often ask for fewer investigations than would be asked for [from] one of my peers… so less tests, less interventions, by involving parents in the decision making is a simple way that costs can be reduced and systems being more efficient.” **Ajeet, HCP**

Experiencing value through co-creation could, therefore, lead to HCPs striving to deliver more collaborative healthcare for patients.

My observational data showed access to healthcare professionals in an informal setting was of particular value to the public, especially those with chronic or potentially recurring conditions (Fieldnotes: 04/12/2015). These interactions offered opportunities outside of formal clinician-patient consultations to ask questions or raise concerns.

6.2.2 Tangible Value

Healthcare innovations provided examples of tangible value with products that were visible and easier to demonstrate to those who were external from the co-creation process. The spread and sustainability of the innovations reinforced tangible value.

Examples of tangible innovations were seen in sub-sections 5.3;5.6;5.7. The public and HCPs in initiative Woke co-created a document to improve the management of medications across different care settings (5.4.4). This document was seen to have value by HCPs, the public and health and related organisations across the UK. Deanna (Public co-creator) used the document while on holiday to access emergency primary care for her partner. The GP saw the document in use and recognised its value in this interaction, and requested the document for their practice which was located hundreds of miles away from the improvement initiative. People outside of initiative Woke saw the artefact as having value because of its tangible nature and experiencing its usefulness through its use.

Further evidence of the tangible value of co-created innovations was demonstrated by their spread. Some innovations spread within and across geographic and organisational boundaries:

> "We have… a European presence and our patient versions [of information on health conditions] are sold all over the world, translated and sold in Poland. There's a huge market in Poland." **Salima, Public**

These public co-creators helped increase the visibility of the team's work beyond its initial scope, and across boundaries that HCP team members did not as readily or easily travel, corroborating Renedo and Marston's (2014) findings. The public worked with HCPs outside of the core improvement initiatives' teams to spread innovations, and became seen as people with useful knowledge for individuals and organisations beyond the initiative's initial scope.

Finally, innovations deemed of tangible value were viewed as likely to sustain. Isabella (Public) gave an example of working with other public and HCPs to co-create a series of educational tools about a chronic condition for GPs and nurses in primary care settings. As part of this, the co-creators also trained people living with the chronic condition. Isabella stated these educational tools made a difference to the improvement initiative at the time. They provided tangible tools to support and educate the HCPs, and inadvertently people living with the chronic condition through their HCPs providing more informed care. Isabella noted "I think that package is still on the [national organisation] website somewhere so I guess they still think it's useful", and this continued acknowledgement of the tools demonstrated for her their ongoing value.

6.2.3 Value at the intersection

Some co-creation activities realised both experiential and tangible value and therefore sat in the intersection. In these situations, co-creators had beneficial or positive experiences through co-creation and they or others could have better experiences of healthcare because of co-creation. Additionally, the initiatives were able to evidence some form of tangible value.

An example of co-creation activities in the intersection within existing, traditional healthcare systems came from initiative Connect's supported use of an App during screening (5.6). The App aimed to screen for a chronic heart condition bypassing the need for an echocardiogram. This would, therefore, save time for the person who had to be screened and money for the NHS. While the App could be said to have tangible value, it shifted into the intersection because of a process initiative Connect created to support HCPs to use the App. This process provided one-to-one support where the HCPs could experience using the App and were taught how to screen people for the condition (Fieldnotes: 15/03/2016). There was additional ongoing support provided, including through the use of a messaging app where HCPs could flag queries about screening results with hospital-based Cardiologists.

Community Health Workers (CHWs) are a good example of PHCP co-creation that are situated in the intersection between experiential and tangible value. Variations of this approach were used by organisation Jinja in Sub-Saharan Africa, and initiatives Connect, Samaaj, and by Krisztina in the UK. CHWs were members of specific geographic, social, linguistic or other communities who facilitated interactions as conduits between communities and formal healthcare structures. These interactions underpinned a variety of PHCP working. For example, CHWs triaged the public through formal healthcare structures and helped them better manage their healthcare conditions. They worked with HCPs to provide supplementary healthcare services or education. In summary, this model bridged the intersection because it realised experiential value for co-creators and enabled the public and HCPs to have better experiences of healthcare systems. Additionally, the model could tangibly demonstrate that this way of working achieved results. Therefore, it could demonstrate value for those part of, and external, to the process.

The CHW model realising experiential value was crucial to its success and sustainability as most CHWs were unpaid in the initiatives studied in this thesis. The model's success relied on a movement of individual CHWs interacting with other public and with healthcare systems and as such, they needed to experience value from their role which went beyond performing useful tasks alone. Feeling valued was a crucial factor to sustain involvement for some CHWs:

> "Because if they don't feel valued, you're not going to sustain anything because they may come in and do the training and say, "well, what am I doing this for? Yes, I'm helping my friends, I'm helping other people, but it's not worth my while because it's not really valued anywhere down the line."" **Assata, Public (initiative Samaaj)**

CHWs delivered more tailored, responsive healthcare for other public. They shared information about specific health conditions or services with individuals and communities, and gathered information about their needs. This was possible as CHWs shared characteristics with these communities and were able to interact with them in ways HCPs were not. Common characteristics included speaking the same language, literally and proverbially, and familiarity with communities' cultural practices. HCPs could then deliver more timely care to people who they may otherwise not see:

> "But the biggest change that they make, or two changes I suppose, is that [CHWs] help women get to antenatal care when they may not have been able to find it, they may not even know it exists. They may know it exists but not have the language skills to access it, those sorts of things… And the other big benefit that these volunteers always get trained in, is breastfeeding support. So they support the initiation of breastfeeding, and postnatal care generally..." **Krisztina, HCP**

Organisation Jinja and initiative Samaaj collated data to objectively demonstrate the value of CHWs to those not actively engaged in the process. This enabled Jinja to demonstrate the added value that CHWs had in comparison to initiatives which did not use this way of working:

> "that type of work does yield significantly different results from working business as usual, not engaging patients. Now we also have the comparison for the rest of the country which does not show that [difference] when these methods and these approaches are not used. Also [national initiatives] have recognised these accomplishments in [Sub-Saharan African country]… they've actually given what they call their top performer sort of recognition... So not only does it make sense, not only do we have the experience of it,

> but we actually have the data that shows that, and it's recognised [nationally]."
>
> **Serj, HCP**

CHWs then successfully bridged experiential and tangible value and realised demonstrable value for those directly part of the process and those external to it.

6.2.4 The Experiential-Tangible Value Model: A summary

The three forms of value (experiential, tangible, and the intersection) described in sub-sections 6.2.1-6.2.3 are now presented as the Experiential-Tangible Value model (Figure 18). This model was constructed from the data to demonstrate factors that influenced why co-creation would be deemed to be, or have realised, value. The model presents a fluid, non-binary, categorisation that aims to describe and not judge the value realised by co-creation. Experiential value could be a precursor to tangible value being realised, and tangible value could lead to experiential value. For example, some healthcare innovations enable people to have better healthcare experiences. Similarly, experiencing the value of co-creation encourages people to continue working together thereby increasing the possibility that they will realise tangible value. Tangible value tended to be more visible to those who were not part of the co-creation process, and it was easier for people who were part of the co-creation process to appreciate experiential value. Figure 18 first presents the Experiential-Tangible Value model with the various types of value. For the ease of presentation, Figure 19 shows the same model with examples from the data that demonstrate tangible or experiential value, or both.

The Experiential-Tangible Value model provides a discursive tool for public and HCP co-creators to reflect on, and discuss, value more explicitly throughout their initiative. The model aims to initiate discussions among co-creators and help them consider the value of their improvement initiative, and how they work together. Both public and HCP co-creators could use the discursive tool to define the value they think they are realising at various points throughout their journey. Regular reflection could then help public and HCP co-creators assess whether they are currently evidencing value that is useful and appropriate for key stakeholders. Such reflection, and the related discussions, can then influence whether the co-creators need to carry out additional work to realise or evidence the desired value.

Figure 18: Experiential-Tangible Value Model

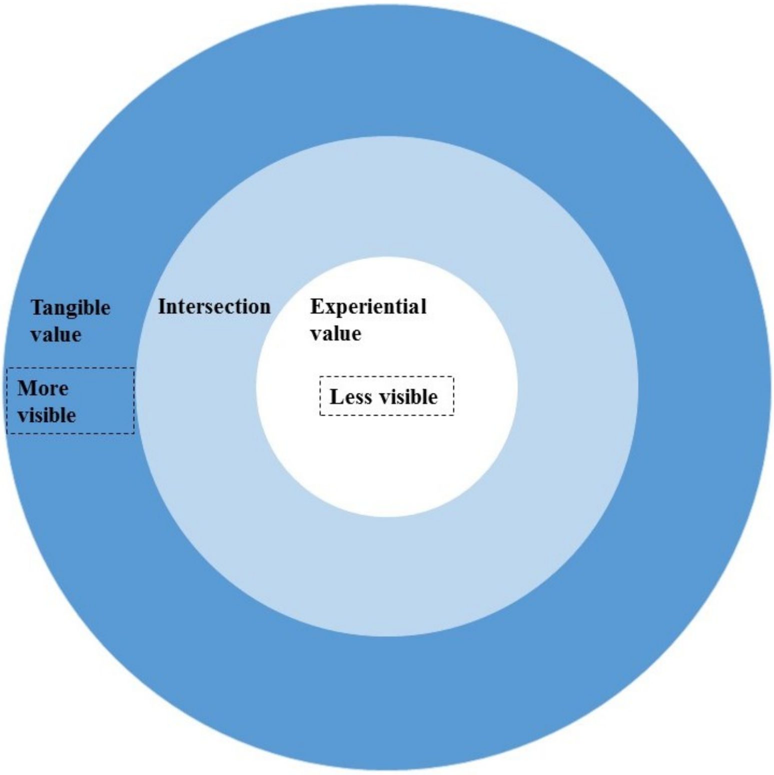
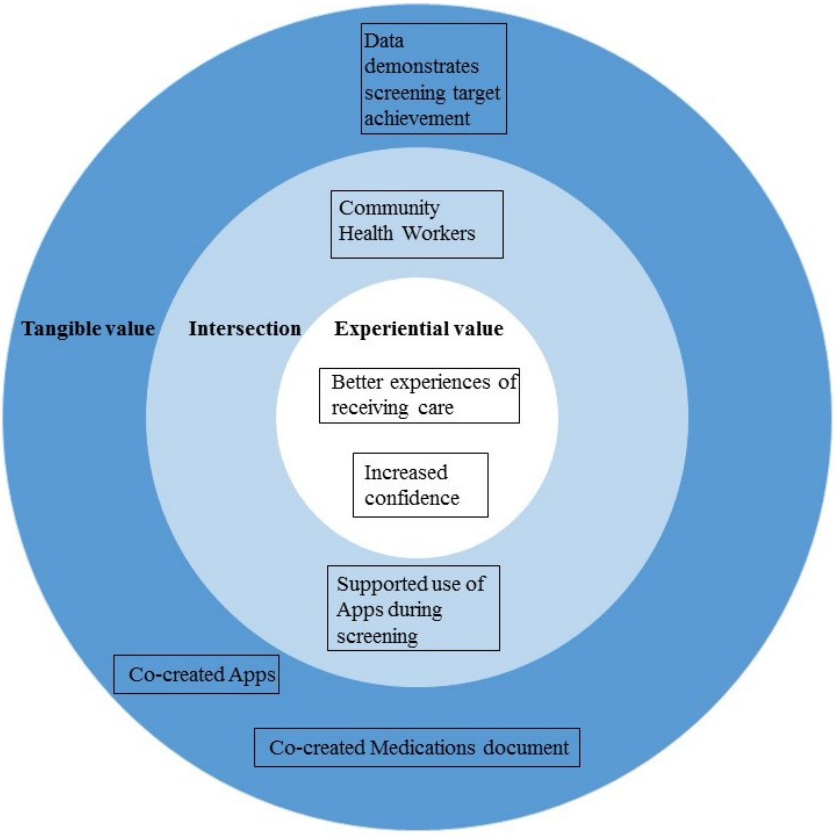


Figure 19: Experiential-Tangible Value Model with examples from the data



6.2.5 Influencing factors: Being part of wider improvements

PHCP co-creation was more likely to be deemed to realise value if it were part of wider improvement agendas or initiatives. People sampled in my research felt there needed to be a unifying purpose to co-create, going beyond enforcing a democratic right of individuals to participate in decision making. Both public and HCP co-creators were motivated and united by an overarching aim to improve healthcare and make a difference. Co-creation was more likely to realise value for healthcare improvement through efforts that provided frequent opportunities to come together. Wider structured healthcare improvement efforts connected PHCP co-creation to the bigger purpose or aim, and provided evidence that this way of working was part of something meaningful (5.7). Wider improvement efforts also provided momentum that facilitated the co-creation process. PHCP co-creation and the value it achieved was limited if it happened in isolation without regular structured healthcare improvement efforts or without a clear purpose, and therefore lacked the necessary momentum:

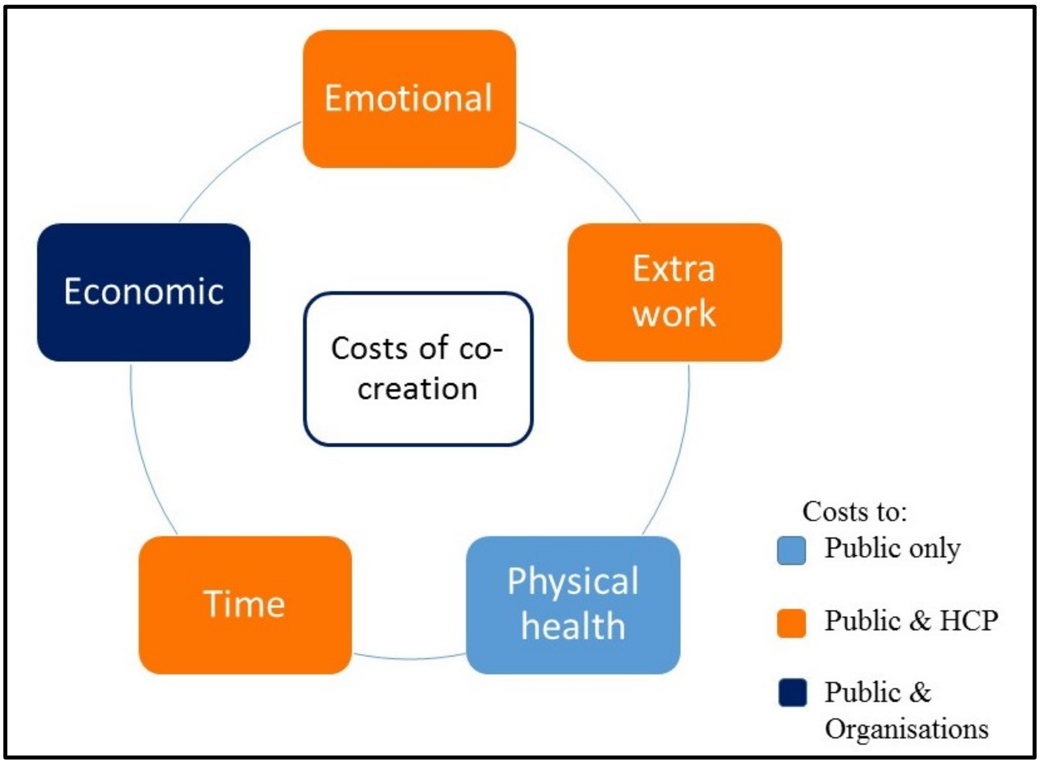
> Jugat shows that healthcare professionals and patients can achieve value, but that the value achieved can be limited by the momentum and actual outputs from improvement initiatives. If there are no outputs, then it doesn't work. There needs to be synergy between the involvement and the improvement initiatives.
>
> **Reflection, Field Notes 30/06/2016**

My data showed co-creation had value which was defined differently by different individuals, in different contexts (5.4;5.5;5.6;5.7). This, therefore, corroborated other research that value is "always uniquely and phenomenologically determined by the beneficiary"[353].

6.3 Costs of Co-creation

The data highlights costs of co-creation for individuals and organisations in five key domains: economic, emotional, extra work, costs to physical health and time. Public co-creators experienced costs in all five domains in contrast to HCPs and organisations (Figure 20). These are discussed in the sections below.

Figure 20: The costs of co-creation



A summary of these costs is shown in Table 12 and are expanded on in the sub-sections 6.3.1-6.3.4.

Table 12: Summary of the costs of co-creation

Costs	Public	HCP	Organisation
Economic	Travel expenses; Printer cartridge; Venue*; Donating money for improvement*; Not claiming expenses because of the laborious process		Room hire; food; travel costs for meeting attendees; wages of the public* or HCP, driving co-creation; training costs for HCP and sometimes public
Emotional	Lack of emotional support	Feeling personally attacked	
Physical health	Makes them ill		
Time	Takes time away from other pursuits or jobs	Takes time away from patient care	
Workload	Expected to do more	Adds to existing workload & pressures	

* - typically a rarer cost

6.3.1 Economic Costs

The economic costs of co-creation were monetary, and affected organisations and the public with no evidence from my data that it affected HCPs directly. This sub-section describes the costs to the organisations and the public, and then presents the debate that existed in the data about whether the public should be paid to shape healthcare improvement.

Organisation's costs

Costs of co-creation for the organisation included room hire, food, and travel costs for meeting attendees. Data from organisation Monitor highlighted regular face-to-face meetings were expensive and took up a significant amount of the budget allocated for co-creation. The organisation was reviewing whether this was the best use of these funds, or whether they should be used for other co-creation activities. However, Aled (Public) shared while he sympathised with this predicament he and his public colleagues felt these meetings were "difficult to replace". An unresolved challenge was how to use the money available in a way that was seen as beneficial for the public involved and for the organisation.

Public paying to co-create

There were various examples of public contributing financially as part of their commitment to service improvement because "it still tends to cost you money to be a volunteer" (Salima, Public). Several of the public participants in improvement initiatives in the NHS did not claim expenses because they found the financial processes laborious for the small amounts they were claiming. Conversely, some HCPs appeared committed to provide expenses to the public but were unaware of how to do so. In practice, therefore, costs such as printer cartridges, telephone, and travel costs were met by public co-creators. These costs led to a sense that financially stable public were more likely to be able to continue longer-term co-creation.

To pay or not to pay public co-creators

The majority of the organisations sampled did not pay public co-creators, or paid them small amounts of money to cover expenses. Organisations Ekta and Tayjan were the only exceptions and described paying public co-creators.

Some public co-creators accepted being unpaid, but mentioned difficulties this brought and welcomed paid opportunities. Pete (Public), for example, was the only public participant in this research who felt strongly that “my time’s always free because I’m a volunteer”. However, he also expressed irritation about not getting paid for co-creation activities despite being promised payment, and appreciated payment he received to train HCPs (Fieldnotes: 09/12/2016). Similarly, Inderjeet (Public) only brought up the difficulty of not being paid towards the end of an 80 minute interview. He initially focused on only the positive aspects of co-creation but later described some of the considerable financial costs he faced because of the amount of unpaid healthcare improvement work he undertook.

There were wider implications of the public being unpaid, for the improvement initiatives and the organisations, when there had been an existing culture of payment. It was unclear, in the two examples showing this, why organisations would go against the norm and not pay, or stop paying the public. In both situations, this led to disengagement and disenfranchisement by potential public co-creators. For example, a hospital trust had active PHCP co-creation but then stopped payments for the public. This was seen to undermine the previously established co-creation culture and activities, which ultimately broke down the respect that had been built up as “nobody turned up anymore… they just seem to think that [public] are an untapped resource” (Ezra, Public). Organisation Jinja took a countercultural approach and did not pay the public which created resistance. There was tension between wider norms of payment for participation in development initiatives and engaging the right public in QI:

> “So what we see at first is a lot of resistance just because we’re asking people to volunteer, and they’re not getting paid. And so they might ask for a t-shirt or some other identifier, something that gives them some prominence in the community so that they’re both legitimate as a QI team member but also it gives them some status.”
>
> **Arundhati, HCP**

This lack of payment reinforced the view that non-payment could undermine co-creation activity and the value placed on public co-creators.

6.3.2 Emotional Costs

The emotional costs the public and HCPs described dictated a need for resilience and highlighted an absence of emotional support, in many cases, for co-creators throughout the process.

Some HCP co-creators mentioned feeling criticised for aspects of care they delivered, or being blamed for the public's previous negative experiences of care. They found this difficult, especially when they felt they had delivered a high standard of care. HCPs occasionally felt positioned as representatives for a healthcare system that had wronged the public, even if they had not been any part of the previous care. This led to negative co-creation experiences in some examples, that were emotionally difficult for HCPs, particularly those committed to collaborative working with the public:

> "of course some of their experiences…make people very angry and very frustrated and if they don't feel that they're being heard they're then inclined to either sort of assume the worst…of everybody…We got this group who were very experienced…in user involvement and they at times were almost turned into the enemy by the group of service users… The relationship was actually really, really difficult, and quite stressful for the staff involved…" **Astrid, HCP**

The commitment of these HCPs to working collaboratively meant they did not want to stop working with the public; however, it took effort to manage these emotionally charged situations when they received the brunt of the anger.

Public co-creators had similar experiences and stated organisations and initiatives would not afford them the same level of support that may be available for employed HCPs. The public were often lone workers, or worked in small groups and, therefore, did not always have colleagues whom they could turn to for support. They did not have regular one-to-one meetings to support effective and healthy working. Therefore, some public participants found it difficult to flag emotional aspects of co-creation with HCP colleagues. Furthermore, if they were positioned as conduits between healthcare systems and other people with related conditions, they took on additional emotional aspects of care when speaking or supporting fellow public. Inderjeet (Public), for example, described the emotional costs he faced running a patient support group for people diagnosed with cancer:

> "…I do get phone calls as well. And emails… I've had one earlier this week from a guy who has got metastasis in his liver and lung now so it's not good news and I've, I've not had any training at that and I think that would be handy in terminal diagnoses… There is a huge emotional cost. [MK: Do you get support for that?] No." **Inderjeet, Public**

6.3.3 Time

Co-creation between HCPs and the public required time. It was a slower pace of working which required both the public and HCPs to make significant commitments.

HCPs would frequently mention existing pressures on their time related to working within an increasingly strained system. They highlighted the impact of staff shortages on their desire and ability to engage other colleagues to carry out healthcare improvement. They often struggled to deliver their ‘day job’ which meant there needed to be a powerful motivator for HCPs to carry out healthcare improvement. Time committed to QI was perceived as time taken from patient care (5.7). The time constraints for co-creation mirrored those for QI. HCPs not already committed to co-creation struggled to find the time for this way of working, and working with public became an even lower priority for them (5.6).

Public partners committed significant amounts of time to contribute to healthcare improvements. While the majority in this study were retired or did not work due to ill-health, one public partner, Neena (initiative Jugat) was employed full-time in an unrelated profession. Neena was so committed to the HCPs and the aim of the initiative that she took annual leave to participate and did not perceive this as a personal ‘cost’ for her:

> **Interviewer: “How do you respond to me saying that that’s quite a commitment to take annual leave?”**
>
> **Neena (Public): “**Yeah, it’s funny you should say that… that wasn’t a waste of a day’s holiday, no it wasn’t, it wasn’t a waste at all... I would take leave again in the future to come to such meetings.”

HCPs appeared to place greater value on their personal time commitment than on the publics’. This value was evidenced by the behaviours of public or HCP co-creators. HCP team members’ work habits and practices were different to the public, and structured particularly by traditional healthcare settings and their patient-focused roles (section 4.1). These work habits and practices facilitated ways of working for HCP but not public co-creators. For example, the public would not always be aware of late changes to improvement initiative meetings and time was lost turning up to the wrong place or arriving after the meetings had started (Fieldnotes: 01/07/2016). Conversely, HCPs were more likely to take more expensive forms of transport than the public partners partly due to perceptions about more important commitments on their time:

> "…some of our [clinical] steering groups… the expectation they have on cars coming to get them and… getting black cabs everywhere, where we have patients who are in wheelchairs…standing around at [train station] for three, four hours waiting for peak time to finish so it's cheaper for us… the [clinicians] think their time is more precious, they've got a job to do and they're saving lives, and maybe that is true, and a lot of our… members are volunteers who are retired, who have… time, even though they've got bad health, but they feel that that's the way it should be." **Mia, HCP**

6.3.4 Workload

Healthcare improvement and co-creation increased the workload for HCPs and the public. For HCPs the extra workload related to the time pressures they faced and mentioned pressures in the system that pushed them to deliver more within their jobs, leaving them struggling with the extra workload required for healthcare improvement and co-creation. Organising meaningful co-creation activity ultimately took non-existent time from busy HCPs (5.7). This lack of time in turn increased the workload for public co-creators, who would be expected to do ever more by HCP colleagues (5.6).

Co-creation led to extra workload for the public by impacting on their personal lives or other commitments. Many public co-creators' experiences demonstrated the initial co-creation role became a gateway into the healthcare improvement, and to new and additional roles for them. As the public continued to participate, their knowledge and experience of complex healthcare settings and conditions made them sought after by organisations and HCPs, and this could be deemed a benefit by the co-creators. But PHCP co-creation could become constant work for public partners and they felt HCPs were less likely to remember that this was not meant to be full-time work for public partners:

> "I have to remind them I'm a volunteer and…I'm not a paid up employee of them, of the organisation, because… the demands on you increase the longer you're with them and sometimes I have to say, "well I'm sorry I can't do this or I can't do that because I don't want to and it's getting in the way of…other voluntary work I'm doing." **Taylor, Public**

Yet, as discussed in this chapter, even if the public co-creators desired opportunities for longer-term employment, these did not always manifest.

6.4 The dichotomy of co-creation: making Charlotte ill while saving her life

Charlotte's unique experience highlighted the potentially dichotomous nature of co-creation and made this an example worthy of further consideration. On one hand, she described how co-creation impacted her physical health, while on the other she credited co-creation with saving her life. Charlotte's experience revealed the nuanced nature of co-creation. Thus, only exploring benefits and costs could oversimplify the value of co-creation. It is, therefore, useful to consider the wider co-creation experiences and not focus solely on examination of the costs and benefits.

Charlotte was the only interviewee to mention that co-creation affected her physical health. Her life switched between living in long-term residential care and her co-creation activities. Her experiences highlighted different work habits and practices between HCPs and the public. HCP practices and habits appeared to be structured by the systems in which they worked (sub-section 4.1.4), whereas for Charlotte this conflicted with practices and habits developed in relation to where and how she lived. This caused her anxiety. She felt HCPs working patterns did not consider her personal work-life balance and her ever increasing time commitment which affected her personal wellbeing:

> "They forget that I never ever get time off. They all go off on their holidays, I don't get a holiday. The job's an opportunity for me, I'm hoisted from a chair to a bed… when working out the diaries it is very much the diaries…for those who are professionally involved, not for those of us who are voluntarily giving our time… time gets limited and then you begin to panic that you haven't got the things ready… and you're letting people down and if you don't do it there's nobody else to do it… and so because I'm so passionately motivated about my cause I push myself and sometimes I'm quite ill as a result. It's not sustainable and it won't be for much longer, I'm definitely deteriorating quite fast now..." **Charlotte, Public**

Despite these concerns Charlotte saw co-creation as an opportunity and a form of escape from her daily life which focused around her condition. This highlights the plurality of perspectives of this way of working, showing potential costs and benefits for one person or from one PHCP partnership. Charlotte's example of the benefits of co-creation demonstrated an interesting response as she associated co-creation with saving her life:

> **Interviewee: "... finally from me what do you think you would be doing if you weren't involved in these projects?"**
>
> **Charlotte:** "I'd be dead. Really, I'm not joking I would have committed suicide… there's no family input, I have nobody but my friends and colleagues… [This work] gives me a purpose, it gives me a sense of value, it gives me a good objective and I'm very passionate about that. I'm proud too and very, very privileged, to have the opportunity to do this."

This example highlights the complexity of the costs and benefits of co-creation. This did not mean benefits outweighed or negated the costs of co-creation for Charlotte, but were in fact two independent parts of her experience.

6.5 Conclusion

This chapter has highlighted public and HCP interactions can co-create value for individuals, and healthcare organisations, and systems (6.1), but there are costs of co-creation that sit across five domains: Economic; Emotional; Physical health; Time; Workload (6.3). Furthermore, whether co-creation is deemed to have realised value varies, depending on how close people are to the co-creation process, and the Experiential-Tangible nature of the value (6.2).

Co-creation enabled individuals to better manage healthcare and enabled them to develop new skills and grow confidence. It helped HCPs to understand the realities of healthcare processes and could encourage them to develop more collaborative clinical relationships with patients. Evidence showed co-creation could enable public partners to better manage health conditions and navigate their way through healthcare systems.

Co-creation increased accountability and improved effectiveness in healthcare organisations. Public partners provided extra pressure that encouraged HCPs to deliver what they said they would. But they were also able to ensure organisations planned and designed healthcare based on actual rather than perceived need. PHCP working led to new ways of delivering healthcare including through variations of the Community Health Workers model. This model provided supplementary, responsive healthcare systems or triaged people into existing healthcare structures. Additionally, the co-creation, use, spread, and sustainability of non-technological and technological healthcare innovations provided ways for individuals to better manage health and care.

This chapter introduced the Experiential-Tangible Value model. This model demonstrates how those were part of the co-creation process could perceive its value differently to people who were removed from it. I showed how experiential value included co-creators believing they had meaningfully contributed to healthcare improvement, and this belief could enable more collaborative PHCP relationships. However, it was the tangible benefits from co-creation, such as the healthcare innovations, that provided more visible value to people removed from the co-creation process. This model could be used by PHCP co-creators to discuss and define the value of their initiative or their co-creation process. The model could shape regular assessments of value among co-creators and remind them of what is perceived as value. For example, during this PhD, apps became a desirable innovation in the English NHS and were, therefore, more likely to be deemed tangible value. This highlights the dynamic nature of what is deemed value. Regular assessment against the model could, therefore, enable co-creators to focus efforts to realise or manage experiential value or increase efforts to achieve tangible or intersectional value.

This chapter therefore contributed to answering the research question:

b. *What value is achieved through PHCP co-creation, and why is it deemed value?*

and provided background for the overarching question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

This chapter contributed an empirical assessment of the value of co-creation and demonstrated its benefits and cost. It answers McKevitt et al.'s (2018) call to investigate how value is produced and for whom[77]. In doing so, this study tests the potential of 'value' to assess the impact of PHCP working and adds to the evidence base for co-creation. Theoretically, value could provide a clearer way to assess the impact of co-creation, however, in practice, it was just as nebulous a term. This nebulosity was perpetuated by value being perceived differently based on those who were part of, or external from, the co-creation process. This corroborates research highlighting the unique nature of value[82], explaining it is defined by the individuals[82,110], and describing co-creation as experiential[89,346].

Finally, this chapter described five costs of co-creation for the public, HCPs, and organisations: Economic; Emotional; Physical health; Time; Workload. Public partners were most likely to be burdened by all five costs, while HCPs and organisations faced fewer costs. Explorations on the costs of coproduction[220] have described similar costs, but do not explain the nuanced nature of co-creation. My research shows the value of co-creation could not be determined by simply taking costs away from benefits. The experiential nature of co-creation meant the whole co-creation journey needed to be assessed to understand both costs and benefits and show the full picture. Charlotte, for example, credited co-creation with saving her life, yet shared that it impacted her physical health. This example could support future use of narrative interviews to advance exploration of the value of co-creation.

This chapter has highlighted the unique, nuanced, nature of the value of PHCP co-creation. But questions remain about what could be done to optimise this value. Research has described the potential of the use of QI methods to facilitate co-creation[113,114]. The following chapter, therefore, makes the most of the context surrounding this research to provide a novel, detailed insight into how these methods facilitate or impede PHCP co-creation.

7. How does the use of QI methods facilitate or impede value co-creation?

> "…you need to have methods that will help with execution and you need to encourage people to be using methods… and we've applied methods to just about everything that we have done successfully in quality improvement in [Country A] and we can reflect back on things that have not worked and see lack of method." **Dave, HCP**

Quality improvement methods were created to primarily improve quality in industrial settings[112,122]. As the quote above shows, such methods are seen as necessary to improve healthcare. They are said to offer a scientific approach that can make explicit healthcare processes and highlight areas that need to be improved[112,133]. Some of these methods aim to centre healthcare improvements on patients' needs and experiences[141,182,183]. This includes collaborative learning and working to improve healthcare quality[119] with some examples involving patients as part of these collaboratives[149]. Evidence states structured methods can facilitate public partners being part of healthcare improvement[49,113,114,142]. For example, plan-do-study-act (PDSA) cycles enabled the public to participate in tests of change and evaluation in healthcare[142]. And Lean can enable the public and HCPs to work together[113], yet may not result in improved patient experience[354]. Renedo et al. (2014) found QI methods provided symbolic resources that assisted public co-creators to transition into new healthcare improvement spaces[114]. They found four factors in an organisation's culture facilitated successful PI, one of which was "the constant and iterative process of data collection and reflection facilitated by the use of quality improvement methods and the commitment to act on that learning"[114]. However, this evidence focuses on a single QI method or has investigated one specific site or programme.

This chapter therefore adds to this literature by exploring the use of multiple QI methods and their relationship to PHCP co-creation across different programmes or organisations. It answers the final research question:

C. *How and why does the use of QI methods facilitate or impede PHCP co-creation?*

This chapter builds on existing research by offering a practitioner-researcher perspective. This perspective comes by my position as somebody who practices co-creation and is interested in researching this practice to improve this way of working. It is from this perspective that this chapter answers the call to shift the focus from why the public and HCPs should work together to explore *how* this can be implemented[74,240]. The previous chapter demonstrated PHCP co-creation could achieve value, but this was not guaranteed because of the related costs and the complexity of what contributes to perceived value. This chapter explores whether QI methods that may already be used routinely could, in fact, optimise co-creation. By exploring whether QI methods facilitate or impede co-creation, these findings could increase the likelihood of this approach realising value by producing generalisable knowledge that could apply across different organisations and initiatives that aim to implement PHCP co-creation for service change.

This analysis was framed using Dialogue, Access, Reflexivity and Transparency[86] (DART) as a middle-range theory. Prahalad and Ramaswamy (2004) describe DART as "the building blocks of co-creation"[260]. These four components are necessary for high-quality interactions between individuals and the surrounding contexts[82,86]. As such, the following study presents the first investigation of whether QI methods facilitate or impede DART in practice. In doing so, it tests whether DART can explain how and why quality interactions between the public, HCPs, and wider systems can be realised.

This chapter is structured as follows. Firstly, it describes how QI methods were used in practice across the various contexts and introduces the DART model. It then demonstrates the relationship between the use of QI methods and PHCP co-creation. Finally, it examines how QI methods may impede co-creation.

7.1 Use of QI methods

This sub-section starts by describing how QI methods were used in examples where PHCP co-creation occurred. It then uses the data to define the relationship between the use of QI methods and the DART model describing how this influenced PHCP co-creation.

7.1.1 Use of QI methods in practice

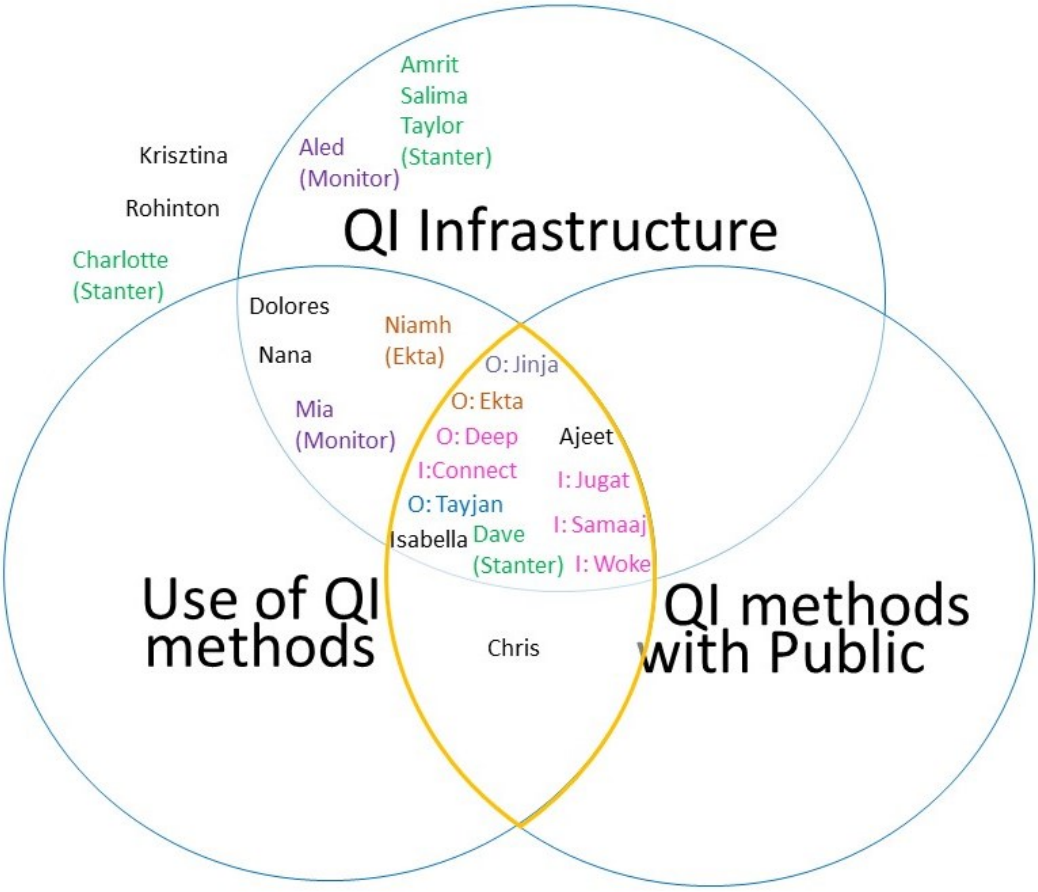
This chapter aimed to understand how the use of QI methods influenced PHCP co-creation across the 6 organisational case studies, 4 in-depth improvement initiative case studies, and data from the experiences of 7 individuals. My data demonstrated these methods were more likely to be used in situations where there was surrounding infrastructure that supported healthcare improvement. This infrastructure was a programme or organisation that was committed to, and supported, QI in healthcare.

Yet, even where this QI infrastructure existed, awareness of the use of QI methods varied and led to some data being excluded from this analysis. Public and HCP co-creators did not always use QI methods. Furthermore, public co-creators were not always *aware* of the use of QI methods as demonstrated in organisations Monitor and Stanter, but HCP were. This therefore led to exclusion of the public co-creators for these organisations. It also led to purposive sampling to gather data from other cases where QI methods were used.

I was specifically interested in the examples where QI methods were used with, or by, public co-creators as represented by the yellow intersection in Figure 21. The data included for analysis in this chapter therefore came from five organisations (including organisation Deep's four in-depth improvement initiatives) and three individuals. Organisation Stanter was included because the participant, a HCP, was able to provide examples of the use of QI methods with public co-creators.

Continued overleaf.

Figure 21 Use of QI methods by organisations and individuals from the data



QI methods were used in all selected studies with some variation in the approaches seen. The most common approaches were collaborative working followed by the use of Plan-Do-Study-Act cycles. Deep used nine main QI methods and the evidence demonstrated other cases also used these (Table 13, pg.196). Some additional methods such as Lean were also mentioned. Sustainability planning tools were only used by organisation Deep and the improvement initiatives it funded and supported. There was variation in uptake of QI methods within the cases, and their use was not standard practice. Additionally, QI methods were always used by or with HCP, while public partners were not always involved.

The surrounding QI organisations and programmes appeared to facilitate commitment towards collaborative working. This was demonstrated in the data from the five organisational case studies (Deep; Jinja; Ekta; Tayjan; Stanter) and the experiences of Ajeet (HCP) and Isabella (Public). In all of these examples, the organisations and programmes promoted collaborative working as a core method to improve healthcare (Table 13, pg.196). Some HCPs from initiatives Connect and Jugat interpreted collaborative working to mean multidisciplinary or intradisciplinary collaboration with other HCPs. For the most part, however, the cases that adopted collaborative working also included public and HCPs working together as part of this approach. These examples positioned PHCP co-creation as a necessary component for healthcare improvement. In these examples, the combination of co-creation and the use of QI methods was seen to provide scientific rigour and help advance healthcare improvement. As Chris (Public) stated, “there’s something profoundly different that can be made to happen if you’ve really genuinely got patients involved, and it’s set up as a proper scientific study.” The data revealed a somewhat synergistic relationship then, between the use of QI methods and PHCP working to improve healthcare.

Continued overleaf.

Table 13 QI Methods mentioned as being used

▨ X = These methods were not used with the public in these organisations

Name (organisation)	**Model for Improvement**	**Collaborative working**	**PDSA**	**Driver Diagram**	**Process Mapping**	**Measurement for Improvement**	**Patient Stories / Journeys**	**Learning spaces**	**Sustainability planning tools**	**Other**
Deep (Org)	X	X	X	X	X	X	X	X	X	
Connect (Deep)	X	X	X	X	X	▨ X	X	X	X	Agile process improvement
Jugat (Deep)	X	X	▨ X	X	▨ X	▨ X	X	X	▨ X	
Samaaj (Deep)	X	X	X	X		X	X	X	X	
Woke (Deep)	X	X	X	X	▨ X	▨ X	X	X	▨ X	
Jinja (Org)	X	X	X		X	X				
Ekta (Org)	X	X	X	X	X	X	X	X		Experience-Based Co-Design
Tayjan (Org)		X		X	X	X		X		
Stanter (Org)	X	X	X				X			
Ajeet	X	X	▨ X		X	▨ X	X			
Chris	X	X	X			X	X			Soft systems methodology; Stakeholder mapping
Isabella			X							

7.1.2 QI environments facilitating PHCP interactions

Dialogue, Access, Reflexivity and Transparency[82] (DART) were demonstrated in the environments described in the data, and facilitated healthcare improvement. The DART components aided interactions between public and HCPs, and between these individuals and the surrounding healthcare systems and structures. In such environments, the use of QI methods could further facilitate DART between the public and HCPs and the wider healthcare systems and structures. Table 14 describes how the use of QI methods facilitated DART, specifically between the public and HCPs, as demonstrated across the data from five organisations and the three individuals included in this analysis.

Table 14 How the use of QI methods enabled DART

	Definition based on Ozcan & Ramaswamy (2014)[86]	**How use of QI methods manifested these**
Dialogue	Between equals through active conversation & sharing views of what is meaningful to individuals.	Brought the public and HCPs together, building relationships between them through facilitated spaces and processes. They enabled co-creators to influence improvement.
Access	Gaining information about experiences, context, tools, expertise, skills etcetera of other agents.	Provided physical access over periods of time to PHCP skills and experiences. QI methods made explicit and provided access to information about relevant healthcare systems and processes.
Reflexivity	Achieving better co-creation by feeding back learning from co-creators, and structures that facilitate co-creation.	QI methods provided structured approaches that encouraged and facilitated regular reflexivity among the public and HCPs of co-creation, and its impact on the improvement initiative.
Transparency	Visibility of information. Implies openness and communication that builds trust.	The methods encouraged explicit documentation that allowed the public & HCP co-creators to monitor and assess key aspects of the improvement initiatives.

The Tayjan case study described below is an example of PHCP co-creation and the DART model provided a useful explanatory theory to help uncover how the organisation established a culture for co-creation.

Tayjan (organisation): establishing a DART-rich culture to facilitate improvement

Tayjan is a hospital in the USA that was prompted to change their relationship with the public when the organisation realised they had poor health outcomes for specific conditions. Senior organisation leaders recognised a need to talk to patients/carers to hear their perspectives about the delivery of healthcare. Some HCPs initially questioned whether this dialogue and degree of transparency was the right approach, but it did enable the public to become part of the conversation:

> "…well, a lot of people predicted that [patients/carers] would leave when they found out we weren't the best, but instead they said, "thank goodness you finally came to us because we've been waiting for you to ask what we think". **Grace, HCP**

This established a reflexive relationship between the organisation and the public, and positioned the public as partners for healthcare improvement. This relationship was facilitated by the use of QI methods, including measurement for improvement type of data collection and analysis. For example, some patients were shown how to collect regular measures and use statistical process control to monitor their own conditions. Carers were provided with more detailed information about treatment(s) they could deliver. The richer dialogue, and greater access to information, therefore enabled patients/carers to take a more active role in their own medical care. This increased both patients and carers' autonomy and ability to actively engage in the care process and deliver more responsive care when needed, rather than waiting for HCPs. As a result of this ongoing dialogue, reflexivity, and increased transparency, the public and HCPs established different, stronger, and more equal relationships than previously was the case. Such relationships were further strengthened when the public and HCPs in organisation Tayjan worked together in improvement initiatives. This enabled public partners to be active participants and engage in discussions at strategic levels of the organisation: "I think it builds this trust in the relationship when [the public are] on the team [and] they're willing to give more real feedback, than if we just asked them" **Grace, HCP**

Organisation Tayjan had inadvertently created an environment illustrative of a DART-rich enterprise and this supported an increasingly reflexive culture which facilitated PHCP co-creation in improvement initiatives. Public partners were employed to support and guide HCP-led improvement teams that wanted to work with the public. Alongside this, there was an increase in training in both QI methods and PHCP co-creation. Over time and through seeing value from working with public partners, HCPs supported individuals to become more equally placed partners in improvement. For example, public partners accessed QI training that enabled them to become leaders and deliverers of healthcare improvements:

> "the parent that led the project… was on [another] project as a mum… and she heard about the training that people had gone through… and she said, "can I take this training, I'm really enjoying this, I'd like to learn this myself…"… and [then] she said, "OK I've got a perfect idea… I can do something with the school-based health work that we're doing" and so the community teams reached out to us and said, "hey, if she wants to do this project we'll sponsor her to take this class" and so she did. And she was one of the rock stars on the class, it was amazing." **Grace, HCP**

Tayjan's initial commitment to improve the organisation and how they delivered healthcare led to a slow and inadvertent shift towards a DART-rich culture. This created a receptive environment and brought together proficient individuals and constructed a positive organisational culture for co-creation. However, there were still sceptics of PHCP co-creation and healthcare quality improvement within this positive environment, and some HCPs remained unconvinced to work with the public as partners. This group were not interviewed as part of this study and further exploration would be useful to uncover their practices and views. Such data may challenge the extent to which Tayjan is a DART-rich culture, or question whether DART always facilitates co-creation experiences[89].

7.1.3 Physically bringing people together

The strength of QI methods came through their ability to bring together public and HCP partners to improve healthcare. According to the DART model, this inclusivity is an important part of enabling dialogue and provides some transparency and access for all co-creators. It can, therefore, initiate high-quality interactions between the public and HCPs as was illustrated in this analysis.

The data from all five organisations and Ajeet's (HCP) experiences demonstrated the use of QI methods physically brought together the public and HCPs, and structured their interactions around a shared commitment to improve healthcare. QI methods that emphasised this collaborative process between the public and HCPs, were specifically driver diagrams, process mapping, PDSA cycles, and patient stories. In this context, the QI methods provided a structure to bring together diverse people and perspectives to inform and shape more relevant improvement. For example, having public partners participating in process mapping sessions "made it much more real [for HCP co-creators] rather than it being a theoretical story about theoretical patients" (Ajeet, HCP).

When part of a facilitated process, QI methods promoted dialogue between individuals, and highlighted and provided access to public and HCP experiences, skills, and knowledges. The methods uncovered useful information relevant to the improvement initative, and gave improvement teams structure for collaborative reflexivity between the public and HCPs (fieldnotes: 20/11/2015J and 29/10/2015). This provided more transparency for public and HCP partners of the day-to-day working and any issues in the improvement initiative. For example, it enabled public partners to reflect on the data being collected to measure whether a change was being made (Samaaj, documents:18MMR). This data, together with their physical presence, enabled public partners to provide timely critique:

> "but I found in that meeting that [the public partner] called [the HCPs] to account [and said] "what are we actually doing for the patients here?... they're not benefiting by this form at all like they benefit by having a book and having a conversation about their physical health"… I think that's a great…example of a patient being in the room and influencing the direction of a project." **Igor, HCP**

The physical presence of public partners with access to data was a key enabler to optimise their influence on healthcare improvement.

The physical presence of public partners as facilitators of QI methods in organisation Ekta enabled HCPs to experience the value of both the individuals and the methods. Public facilitators embodied knowledge and experience of QI methods while maintaining their public roles. This enabled HCPs to see the public partners 'in action' as QI experts and experience the knowledge, skills, and abilities they had:

> "…one of our [public partners] yesterday led the session on driver diagrams and developing them and teaching the staff how to use them... and [some HCPs]…feel very differently about it now and they value it as a resource and… they do say to us, "it's great working with that person, they've been a breath of fresh air." **Astrid, HCP**

Public facilitators of QI methods were found in organisations Ekta, Tayjan, and through the experiences of Chris (Public). The facilitators were useful in shifting HCP-led improvement initiatives to consider more collaborative working. These facilitators expanded HCP understanding of working with public partners, and gave the latter a place and position within the improvement initiatives.

7.2 Uncovering realities & improving relationships

QI methods were purposefully used to make explicit the realities or what actually happens in healthcare and improvement initiatives. Improved PHCP relationships was an interrelated and often unintended by-product of this.

7.2.1 Making explicit the realities of care and improvement

QI methods provided a structured way of enabling people's experiences to be part of the whole healthcare improvement process. This was specifically the case with process maps, collaborative working, and learning spaces as demonstrated by the data from Ajeet's (HCP) experience and the five organisational cases (Deep; Jinja; Ekta; Tayjan; Stanter). The results demonstrated the use of QI methods brought public and HCP perspectives and experiences together. Process maps, for example, described the whole care pathway(s) that the public experienced and that HCP teams may not always be aware of: "a mother of somebody with Down syndrome…was describing their transition from children's services into adult services… it was just brilliant having that different perspective of a mum" (Paula, HCP). Similarly, PDSA cycles were used by organisations Ekta, Jinja, and Stanter to plan and iteratively test changes that aimed to improve people's experiences of healthcare. By bringing together the public and HCPs, these tests of change focused improvements on enhancing human experiences, rather than solely focusing on improving mechanistic processes:

> "…one of the areas that [public co-creators] flagged up was how medications are administered on a psychiatric ward…, [they said] "we line up in the corridor and we get medications, we don't think that's a human way of doing things or offers appropriate privacy. Surely we can change that." They went and worked with the [HCP] team to… design a new system for administering medication and so they're involved in [planning] what the changes might be and certainly involved in does this feel better, does this feel like what you're looking for." **Dave, HCP**

As described, these QI methods facilitated dialogue between the public and HCPs, provided access to information and transparency about processes of care, and enabled reflexivity to improve these processes.

Patients' experiences and journeys as a QI method often humanised what may otherwise have been a theoretical or mechanistic process. Public and HCP participants in this research found such experiences powerful stimuli for improvement. They saw them as stark, necessary examples that uncovered the realities of receiving healthcare of which HCPs may not be aware. Some QI organisations and programmes encouraged HCPs to position these experiences and journeys at the heart of healthcare improvement. This produced a rich, productive dialogue between the public and HCPs. For example, Ajeet (HCP) spoke of a QI programme that encouraged HCPs to shadow patients. Ajeet shadowed a one-year old boy with asthma admitted onto the ward where he was a consultant. He realised through shadowing and observing the care that simple developments could be made to improve patient's experience:

> "... his oxygen level started falling… so there in front of me he was desaturating and the alarm was going off… but because the door was closed the nurses couldn't hear the alarm. It was insane…I asked the mum, "what are you thinking?" She says, "well I know this isn't right and I'm worried about him but I can see the nurses walking by outside and they look quite busy, I don't know whether to call them in..." And in the end I just had to go out there and…say "someone needs to look at this child and increase the oxygen". So it was a really powerful experience for me because… we did two things. We increased the volume of the alarms so they were more audible, but secondly, we put a sheet of paper into each room… which the parents would automatically read saying, if the alarm goes off do not hesitate to call the nurse or pull the alarm cord… and neither of those interventions cost anything. But it made a huge difference to parents like her..." **Ajeet, HCP**

These experiences helped to initiate improvements by enabling HCPs to understand multiple perspectives of healthcare delivery. Specifically, they enabled reflexivity and access to information useful to shape improvement efforts and uncover healthcare experiences. Some HCPs noted that these journeys and stories were not enough on their own and could have limited or short-term impact explored in sub-section 7.4.1.

QI methods provided some public co-creators with tools to increase accountability and learning in the improvement initiatives. This was evidenced in organisation Deep and the in-depth case studies detailed in Chapter 5. For example, Bishn, (Public) in initiative Woke felt "one of the most aggravating things in life is that you make suggestions that then get lost" (Bishn). He had learnt about measurement for improvement through the project and was keen to use this method to monitor the changes, however, the HCPs were less engaged with this unfamiliar method. Bishn persisted and the team eventually responded and started to use the method to monitor whether changes had led to improvements. In a similar manner, Pete (Public, initiative Connect;5.6) had previous experience with QI methods and demonstrated that these could provide useful learning. He used QI methods himself to monitor initiative Connect's progress and evidence learning:

> "[Pete] has been doing PDSAs, he's been talking to the teams about what they should do, and… especially with the measurement for improvement… there were issues with that. And he was one of the people standing up and saying, "We need to learn from this, make sure we don't do it again". Which is quite interesting, to be honest." **Igor, HCP**

These methods could validate public co-creators' involvement in the initiative and provide them with a way to navigate their role through the improvement process. This was specifically the case for Bishn and Pete who were part of improvement initiatives surrounded by a programme that mandated the use of specific QI methods.

7.2.2 Validating public team members

QI methods could strengthen public co-creators' place and position within the improvement initiative. Methods such as driver diagrams gave them access to the rationale of the initiative and the drivers that may facilitate that change. This increased public partners' understanding of the improvement initiative and validated public co-creators' position to themselves or others. Neena spoke of the facilitated adapted driver diagram session in which she participated as part of Jugat. During this session she voted on what the initiative's priorities should be, which in her mind cemented her place in the team:

> "…I was rather pleased actually because my actual top three were the same top three as the professionals…Just being a patient, I thought am I completely wrong here? Because so many of the things were obviously words that I didn't understand… and I thought, wow, that's really good that…they're thinking the same as me and… my answers aren't stupid because that's…the general consensus." **Neena, Public**

This increased Neena's confidence which manifested in her continued, active participation throughout the initiative.

The data from Chris's and Isabella's experiences, and organisation Ekta in particular, highlighted that having knowledge of QI methods provided public co-creators with a level of validation needed for them to be positioned as leaders of improvement initaitives. All public co-creators who led improvement initiatives had pre-existing knowledge of QI methods or were given this knowledge before leading initiatives. Some public partners such as Chris or Ezra, saw these methods as crucial to achieving sustainable improvements. However, for others, knowledge about QI methods was important to enable them to effectively navigate the healthcare improvement sphere. Some public partners felt knowledge about QI methods enabled them to understand the processes:

> "…it's like when you go to France and you learn how to speak French… When you work in quality improvement it's the bit about how to learn the language. Because we have this thing about people need to speak in plain English when they're working with you, but actually if you're working on a [QI] project there is some technical stuff that you need to know as well, so you're better understanding what that means and, and how it works."
>
> **Niamh, Public**

Knowledge and experience of QI methods, therefore, helped position the public as technically-able co-creators. There was no evidence however, that a lack of awareness of methods impeded the public from participating in healthcare improvement. In fact, particular organisations such as Stanter and Jinja did not feel it was always necessary to equip public co-creators with the knowledge of QI methods, but these co-creators would be present in improvement initaitives when such methods were used. These organisations only provided training in QI methods for HCPs.

7.2.3 Improved relationships

QI methods provided a way to structure how the public and HCPs worked together. My data demonstrated the use of QI methods brought together the public and HCPs, enabled them to establish dialogue, share information, and thus build relationships over time. This could improve relationships between HCPs and the public in their own care and for service change.

An example of the former is the public having access to, and managing, data that can in turn support richer dialogue between themselves and their HCPs:

> “we’ll have children who are… diabetic and tracking [and testing their] bloods, and at that level it’s their own personal way of… looking at their data to come back and share with the clinicians what they’re doing and how they’re taking care of themselves as part of their self-management….” **Grace, HCP**

Additionally, public and HCPs in Woke (5.4) used PDSA cycles to create a medications document, and Jinja used these cycles to formatively test ways to engage target populations (7.3.2). Along with other examples from the data, these corroborated existing evidence that PDSA cycles formed an iterative way of working that could establish and embed partnership between public and HCP team members[142]. These cycles formed a transparent and reflexive way of working. The actions planned would be clear to both public and HCP team members, and both groups could actively reflect on what happened in practice. This cyclical, iterative way of working helped structure how the public and HCPs worked together, especially when they still did not know each other.

The following example from organisation Jinja provided an interesting illustration of how the use of QI methods inadvertently overcame stigma and shifted the relationship between public and HCP partners.

Organisation Jinja instigated an improvement initiative in which HCPs were required to work with public partners with HIV in Eastern Europe. There was significant stigma attached to the condition at the time in the specific country in which this initiative took place, including among the HCP team members leading the improvement initiative. They feared close contact with the public partners and believed the condition was the public partners’ own fault. The behaviour of the HCPs meant the two groups would not sit together to eat lunch. This stigma had underpinned how healthcare services for people with HIV had been designed. As part of the improvement initiative, QI facilitators brought together these two polarised communities to process map healthcare from their own perspectives. This method initiated dialogue that enabled the partners to uncover the realities of care. It provided a space for public partners in particular to share access to their individual expertise and experiences:

> "Providers would say, "well this is how it works", and the patients would say, "no that's not the case" or "this is why we don't come back", and so the process of trying to draw a [process map] actually helped them start to see, "oh what I think is happening isn't really happening"… and so that was a point at which it helped change perspectives… Our goal wasn't to help improve the relationship that way, but in the process of using it, it became a tool to be able to facilitate that relationship building...[and show] that these [public partners] weren't just society's throw aways, but they were people who deserved care and support." **Arundhati, HCP**

In this example, QI methods enabled the PHCP partners to reach a depth of reflexivity that they were unable to achieve in their polarised state. It demonstrated that the public partners had something to bring to the improvement process and substantiated their role and participation in the HCPs' eyes. Over time, this broke down the fear and stigma the HCP partners had for those living with HIV, and the public and HCP team members formed a different relationship including eating lunch together. HCP team members would proactively check in with public team members and raise concerns if they had not seen one of them for a while.

7.3 QI methods and improving co-creation

Organisations Deep, Ekta, and Jinja independently realised that the use of QI methods provided structured ways to improve co-creation. Specifically, they saw these methods as facilitating dialogue and reflexivity about co-creation itself. The organisations also hypothesised QI methods could help them achieve a level of transparency about co-creation aims, processes, and outcomes. The similar contexts of Deep and Ekta in particular, enabled a useful analysis of how they achieved this and the impact this had. This sub-section therefore focuses on data from these two organisations and brings in examples from organisation Jinja in sub-section 7.3.2.

Co-creation was a central tenet of QI for organisations Deep and Ekta, connected to the similar underpinning QI philosophy that these organisations adopted. The implementation of co-creation was influenced by the values of specific HCP team members who believed the public must be partners in shaping healthcare. These HCP team members would use the underpinning QI philosophy as currency to endorse PHCP working as crucial to healthcare improvement:

> “we thought, where do you start in this world of experience… So we… just thought if we go right back to Deming who we all quote and… pull it back to that [improvement] methodology. We want to just make sure, have we got the voice of the customer? Have we got the voice of the patient involved in our improvement work? Because if we’re improving things without… sense checking it through that vital process [with] the end recipient, then we’ve got it wrong.” **Paula, HCP (Ekta)**

Deep and Ekta shared a similar philosophy which resulted in a comparable use of QI methods. They both embarked on similar journeys to use these QI methods to tackle the challenges they faced to embed PHCP co-creation.

Variation in uptake and quality of PHCP co-creation was a challenge for both organisations. There was a wide spectrum of views from those who bought into this way of working to those who would not entertain it. Such views were rooted in the value people placed on co-creation (6.2):

> “the challenge…is to get your sceptic into a position where they really do work shoulder to shoulder… the problem is that some of the sceptics just aren’t willing to work in that way. They don’t really work shoulder to shoulder because they're often your monocratic individuals who don’t really believe in the value of consultation and collaboration.”
> **Astrid, HCP (Ekta)**

Both Deep and Ekta were keen to improve how the public and HCPs worked together in improvement initiatives, and within the two organisations. Key individuals specifically wanted to shift people towards more collaborative practise for healthcare improvement.

Public and HCP individuals had taught, facilitated, or experienced the use of QI methods with improvement initiatives in both organisations. This included using QI methods to tackle variations in quality of healthcare. Such prolonged exposure and being in environments which encouraged “doing things differently… by…embracing a quality improvement systematic methodology” (Tarrie, HCP, Deep) may have influenced these teams to turn to QI methods to improve co-creation.

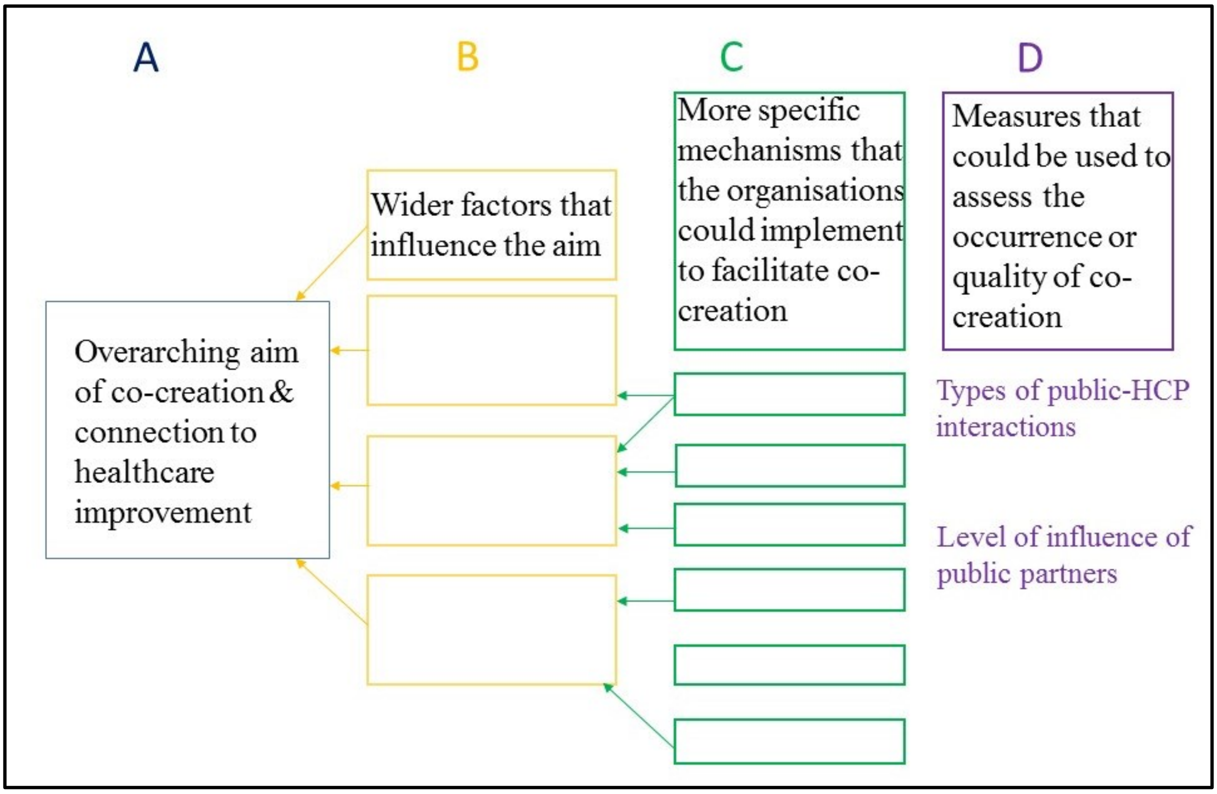
7.3.1 Creating programme theory for co-creation

Individuals in Deep and Ekta decided to practise what they preached and each created a 'programme theory'[126] for co-creation. This meant conceptualising the aim of co-creation and how this could be achieved within their improvement initiatives. Both organisations brought together individuals to conceptualise the co-creation challenge and propose potential ways to achieve this. This was led by PI facilitators in Deep and public partners in Ekta. The process initiated dialogue and reflection about co-creation in a way which modelled how the teams facilitated healthcare improvement. This was considered useful because "very often people… don't have well thought out plans about [co-creation], they just know that they want to do it or think they might have to do it" (Bethan, HCP, Deep).

The Driver Diagrams provided an output that communicated the why and how of co-creation using a QI approach they were familiar with. Figure 22 provides a framework of a co-creation driver diagram constructed from Deep and Ekta's use of this method. The framework shows how the organisations used the diagram to make explicit the overarching aims of co-creation (column A). These articulated a clear relationship between PHCP co-creation and achieving healthcare improvement. Column B were the wider factors that enabled this aim to be achieved. These were quite broad factors such as "availability of resources for involvement" (Deep) or "person-centred care" (Ekta). The mechanisms that could help realise the wider factors (column C) included support for staff and patients (Deep) or co-producing and delivering sessions for Ekta's staff development programme. These mechanisms broke down the overarching aim into the more tangible tasks that the team could enact. Both organisations then created measures that could be used to define and assess the processes and outcomes of co-creation. This included measuring the quality and extent of co-creation as exemplified in column D. These measures provided interesting insight of how the diagrams could support formative evaluation of co-creation.

Continued overleaf.

Figure 22 Sample driver diagram for co-creation



Driver diagrams facilitated the elements of DART between public and HCP partners. They were created through a collaborative, reflexive process that focused dialogue around structuring and improving co-creation. This modelled the PHCP co-creation that the organisations encouraged improvement initiatives to embed. As an output, the diagram made explicit the programme theory[126] of co-creation. In doing so, it increased the transparency of the relationship between co-creation, its potential mechanisms and overarching aims to improve healthcare. Some colleagues in Deep and Ekta were more likely to look favourably on these co-creation driver diagrams, especially as they presented plans in a familiar, accepted method in those contexts. Deep saw their driver diagram as an iterative document thereby enabling PHCP colleagues to continue to evolve it as new information enabled further dialogue and reflection.

The next sub-section uses data from organisations Deep and Jinja to demonstrate how the use of QI methods were used for formative evaluation of co-creation.

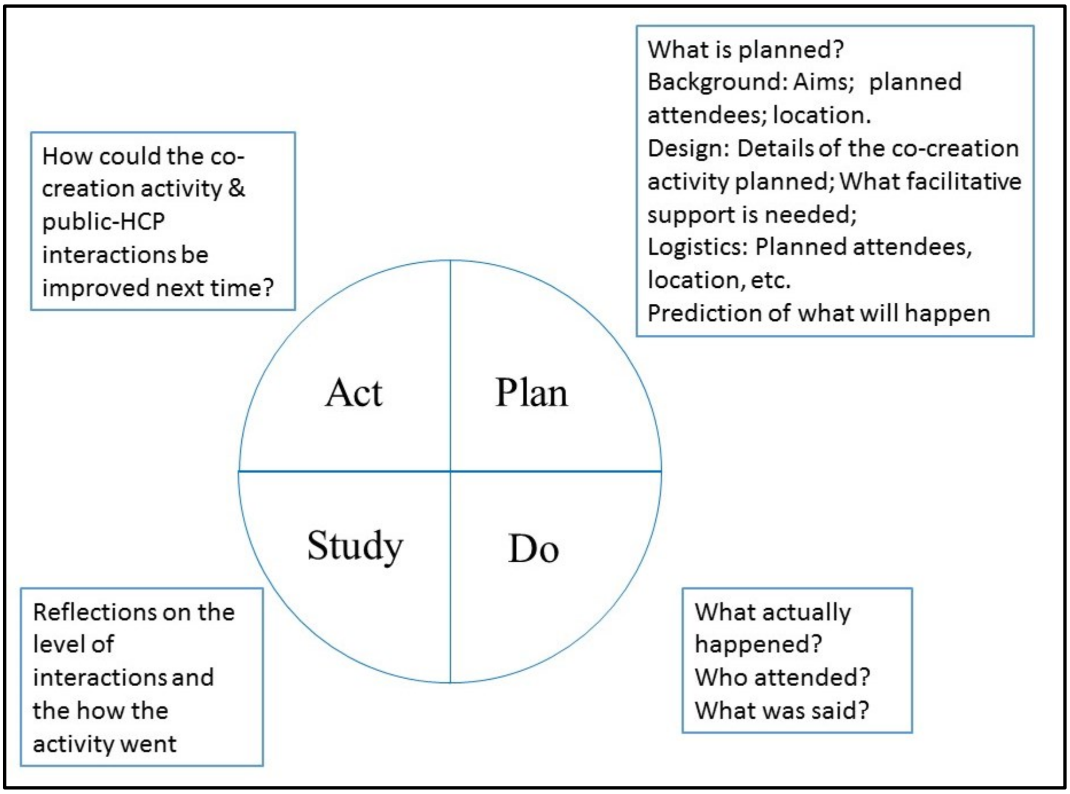
7.3.2 Formative evaluation of co-creation

PDSA cycles were used to document learning and formatively evaluate co-creation. Organisations Deep and Jinja used these to provide a structure for collaborative reflection and to plan and adapt co-creation practice.

In Deep, the use of PDSA cycles as a form of formative evaluation for co-creation was initiated through the collaborative inquiry that formed part of my PhD. The cycles were created by people in organisation Deep, sometimes in collaboration with HCP from the improvement initiatives that the organisation supported. PDSA cycles were used to plan and design upcoming co-creation interactions and activities. Figure 23 (pg.211) provides an example constructed from the PDSAs Deep created. Individuals would come together, reflect on the specificities of these interactions and activities, and 'plan' what would happen, including documenting their predictions of what will take place. In the 'Do' section of the PDSA cycle, they would note what actually happened in practice. Then the individuals would 'study' what happened and reflect, including on positive outcomes or challenges. Adopting this approach made explicit the detailed learning from the interactions or activities. This included reflections from those leading the activities or being part of interactions. For example, the PDSA cycle for one of Jugat's PHCP co-creation sessions noted "there is value in bringing patients, carers and clinicians together" (PDSA1), while PDSAs of Deep organised activities noted participants' reflections: "…it was hard for me to hear, especially participants" (PDSA4I). This would help the individuals with the 'Act' section where they considered what they would do next time, for example "use a microphone?" (PDSA4I). Used properly, these cycles are 'tests of change'[145].

Continued overleaf.

Figure 23 Example use of PDSA cycles for co-creation



Similar to previous findings about the use of the PDSA method, this was often not used with fidelity nor did people routinely complete more than one cycle[145]. This appeared to be because the cycles were often used for sporadic rather than ongoing co-creation activities or interactions. Therefore, while the reflections were useful in shaping future activities, wider factors such as what the HCP-led improvement teams needed to deliver, would have greater influence on the activity design. This in turn affected the extent to which PDSA cycles shaped co-creation tests of change. In some examples, the use of PDSAs fulfilled another role as a mechanism to document the co-creation activities that actually happened, rather than testing changes per se:

> "So… [PDSA cycles were] a good way of keeping a record of what you're doing, why you're doing it, what good would look like, whether or not that happened and what the variations were… I think [the improvement initiative] got that and… they've gone on to continue to use PDSA." **Bethan, HCP (Deep)**

Organisation Jinja used PDSA cycles frequently to test interventions to improve healthcare planning and delivery in Sub-Saharan Africa. The organisations encouraged their community-based teams to use PDSA cycles to plan specific tests of change, particularly whether the PHCP interactions through the community-based teams could successfully target and engage specific 'at risk' groups. They would come together to 'plan' the intervention, then go away and test it, and meet again to reflect on what they had achieved. This then informed their future plans and allowed them to adapt them based on the learning of which co-creation activities led to better health outcomes. This provided a useful and often novel structure for CHWs in particular. One example was using PDSA cycles to test and adapt interventions aimed at encouraging pregnant women to access antenatal care:

> "…we had a team where the priest said, "well I'm a trusted advisor of the family, I'm always one of their first people to know about pregnancy, women will tell me "I'm pregnant""… And, so they took a month… and they try things and one of our coaches said, "well we had 400 different things tried, how many pregnant women did you find?" And of course this priest, who was convinced that he was going to find all the pregnant women in the community, didn't find a single one because women don't tell the priest that they're pregnant... and what we tend to do is to kind of summarise or figure out the best practices... We had a discussion with the team… "what did you see worked the best?" Then we have a discussion with a few different teams, at the same time comparing what they did and what they thought worked, and worked it out to a district level of distilling what the teams felt were the best [interventions]." **Arundhati, HCP**

Jinja used modified PDSA cycles for tests of change that resonated with best practice[143]. These modified cycles provided structure to shape co-creation to improve healthcare, but were adapted to work in different settings.

The examples highlight the use of QI methods to improve co-creation, specifically Driver Diagrams and PDSA cycles. These methods structured reflection and made explicit the connections between co-creation processes and intended outcomes. This would benefit from further research in a wider array of improvement initiatives in different contexts. Such research should test the applicability and usefulness of driver diagrams to shape co-creation in contexts which may not use QI methods. It should also investigate the prospective use of PDSA cycles to understand the potential of tests of change to improve PHCP interactions in initiatives which are coproduced.

7.4 QI methods impeding co-creation

The use of QI methods did not always facilitate successful co-creation interactions because of a lack of resources or commitment; unfamiliarity with the QI methods; perceptions that the methods were not designed for the community setting; and because they were thought to be counter-culture to co-creation.

7.4.1 Lack of resources or commitment

Both observational and reported data demonstrated the use of QI methods could be resource intensive, requiring financial, staff, and time commitment. Organisations were perceived to not support QI if they did not protect the space and time felt necessary for this work, or provide financial resources for improvement. Mandeep (HCP) noted “there’s a lot of lips service paid to QI but no one actually puts their money where their mouth is”. An example of this was organisations not providing backfill for staff carrying out QI activities. This could lead to public team members in improvement initiatives being tasked with using the QI methods as they were seen to have the time to do so (7.2.1). Lack of commitment and resources also led to tokenistic improvement and co-creation practice. Some data highlighted this led to individuals or organisations following structured improvement processes and including public partners, but without a real commitment to allowing them to influence healthcare improvement:

> “there’s some absolutely terrible practice that goes on widely. Literally patients wheeled into the front of the board room and after five minutes of telling a very personal, sometimes traumatic, sometimes really great story, but either way, it takes a massive personal toll to tell that story. Somebody [says]… “thanks a lot but you’re over time now, we’ve got ever such a busy agenda so if you could go and get yourself a cup of tea”… and then the patient is left with a cup of tea, with no connection to the agenda… or to discussion.” **Paula, HCP**

Using QI methods could be seen as laborious, even in environments where QI was supported. Public team members in organisation Ekta were paid and positioned as staff of the healthcare improvement organisation. Part of their role was to facilitate improvements using QI methods. And yet they commented about the time and workload required to use these methods: "it’s been a massive project just to put this one piece of paper together with this driver diagram, and to get it on one piece of paper has been a nightmare as well” (Ezra, Public). Using QI methods, therefore, required a level of commitment, dedicated resources, and a level of proficiency among both public and HCP co-creators.

7.4.2 Unfamiliar methods

QI methods were not always familiar for HCPs and this led to some excluding public co-creators from the process or limiting public influence in other ways.

The data suggests some HCPs excluded public co-creators from spaces where they learn about or use QI methods: “very rarely do [HCP improvement teams] bring patients… Every single time we have an event… usually the only [public] in the room are [our public] panel” (Paula, HCP, organisation Ekta). This was corroborated through the observational data from initiative Jugat, in particular, who would frequently not invite public partners to learning spaces or process mapping sessions (Fieldnotes, 08/09/2016). The findings suggest this was because HCP co-creators were unfamiliar with both working with the public, and using QI methods. For example, the HCPs in initiative Jugat had never carried out a process map so could not describe what was going to happen or inform the public team members of their roles. These HCPs were used to holding the knowledge and providing information to public team members who had largely been their patients. The HCPs in Jugat may not have felt comfortable exposing their lack of knowledge, and this may have then been a factor in them not inviting public team members to learning spaces or sessions when they used specific QI methods:

> Chanan and Mandeep discuss with each other to explore when Chanan would introduce [the e-health platform to patients]. To me, this indicates they may use these QI spaces to talk to each other about these processes and there is still a lot of uncertainty. And they may feel uncomfortable to have these levels of conversations with patients in the room. This doesn’t happen at the [spaces they create to work with public partners].
>
> **Fieldnotes, 8/9/2016**

Lack of familiarity with specific QI methods could influence how HCPs responded to public QI experts. Chris (Public) revealed his improvement practice contradicted normal HCP working. This led to two parallel work cultures which limited the improvements Chris was able to initiate and achieve:

> "…none of the data's presented in the way that I'd like to see it presented. So it's not used for improvement purposes, it's used for ritual beatings really… Basically the [HCPs] don't really see their job as…continual improvement, and are not even sure what that is, and I tried to teach them it in the first year I was there but it was quite clear that I was being a nuisance. So I stopped doing that." **Chris, Public**

The data also shows that lack of familiarity with QI methods led HCP co-creators to be uncertain of public roles and positions in the QI process. This was highlighted during observations of adapted process mapping sessions to plan potential processes initiative Connect aimed to embed. Rita (GP) had invited one of her patients, Max, who had the condition for which initiative Connect aimed to screen. Max (Public) arrived at the process mapping session not knowing what to expect or what was going to happen. The process maps were highly complex and were mapping a potential process that Max could not have experienced. It was, therefore, difficult for Max to participate. Their theoretical nature offered Max no space to share his own experiences of diagnosis and healthcare interactions to manage his chronic heart condition:

Process Mapping session at Bakewell Healthcare Practice.
[The staff from the GP surgery that are] present discuss the details of a text message they are drafting to send to patients to ask them to come in to be screened:
Someone asks "what will patients say in response?"
Rita (GP) says "I don't know, what would you say?" indicating to Max… But then a conversation continues among staff, side-lining Max.
At some point, there is a break in conversation and Max speaks. "I can imagine some patients would be quite alarmed."
There is agreement from HCP and a conversation ensues about whether they need to change the text to alleviate panic.
Anand (QI facilitator) regularly brings Max back into conversation and assigns tasks to him, but otherwise he is not very involved until Rita says "we'll speak to this patient, as well" (and points at Max)

Field notes 07/03/2016

Rita wished to involve Max in shaping and executing the improvement initiative at this process mapping session. However, his involvement in this process mapping session did not lead to transformative change and his suggestions about the text message were in fact vetoed by other patients Rita later asked. These other patients felt the text message should be worded more strongly to highlight the risks of the condition being undiagnosed and to encourage people to attend the screening clinic. Rita and Max continued their GP-Patient relationship after this process mapping session, but Max did not attend any further QI-focused sessions with initiative Connect.

7.4.3 Not designed for the community setting

The data from improvement initiatives in the community setting showed that QI methods were not always viewed as suitable for all settings. The complexity of community settings, in particular, was seen to bring "too many afters and too many variables" (Arundhati, HCP), including large population sizes. Organisation Jinja, therefore, adapted QI methods, and did not use them with fidelity, as they were intended. However, the perception that these QI methods were not suitable for the community setting led to some very vocal opposition to their use by public team members in initiative Samaaj. They felt these methods detracted from, rather than facilitated them, to co-create processes to better support self-management: "I'm a businessman... I don't care about whether this model, or that model is a useful model for doing whatever" (Maynard, Public). Samaaj's Public and HCP team members felt these methods were more suited to clinic-based settings. QI methods could, therefore, create tension or encourage adaptation in PHCP co-creation in improvement initiatives.

7.4.4 QI methods: counter-culture to co-creation?

Organisation Deep initially required their improvement initiatives (in this case Woke and Samaaj) to consider their long-term success using the NHS Sustainability Model[355]. The data from organisation Deep provided interesting insight into how this QI method was deemed to challenge, rather than facilitate, PHCP co-creation.

The NHS Sustainability Model aimed to provide the teams with a diagnostic assessment to understand the likelihood of the improvements being sustained. The model used a series of questions about processes, staff, and organisation. Ideally, all team members individually answer the questions and then a combined score is calculated for each section, plotted on a portal diagram or bar chart to visualise the results and show which factors were more or less likely to sustain.

Both Samaaj and Woke felt this model challenged their participatory ways of working. They thought this method embodied an institutional-mindset that reinforced traditional PHCP hierarchies by making public partners invisible from the improvement process. Cezary (HCP, Woke), for whom working with the public was a new practice, stated the model was "…incomplete because it needs to have patients in there as well… it should be staff, process, organisation, *and patients*". Initiative Samaaj's critique of the model went further. They felt it reinforced hierarchical and traditional organisation-centric language and structures, and did not allow the necessary space for coproduced initiatives to establish their own ways of considering sustainability:

> "I've got absolutely no problem at all with us looking at sustainability. What I do have a problem with is the particular method of doing it, which is so… time intensive, it's repetitive, it's again doing it on *their* form, with *their* words, and I just think they could do it a lot better." **Baljeet, HCP**

Additionally, the Samaaj team, which aimed to improve self-management in the community setting, felt the model was designed for clinical settings. This meant the team would need to translate the model for their context and setting, including through changing its key concepts:

> "coming back out to say patients, organisation and staff, we're all one and the same thing… I think the biggest stumbling block is… having labelled them something like that. I don't consider myself staff, I do not consider this an organisation and none of the people are patients, so that is the first and the biggest step to get over..." **Assata, Public**

The model remained physically inaccessible to some public team members who did not use computers, as optimal interaction with the model was designed to occur via a computer-based method. As such, this model did little to facilitate useful interactions between public and HCP team members and created tension between the initiatives and organisation Deep. Interestingly, continued dialogue and reflexivity between the improvement initiatives and organisation Deep enabled this tension to become generative. This resulted in an alternative method being co-created to consider and plan sustainability.

This model provided a useful example that the promotion of the use of methods could cause tension between the improvement teams and the proponents of the methods, or non-engagement by individual team members with particular methods.

7.5 Conclusion

This chapter provided a novel exploration of how specific QI methods facilitate or impede PHCP interactions, and interactions between these individuals and their wider healthcare improvement contexts. It investigated a range of QI methods that are used in different organisations or programmes to answer the question:

C. *How and why does the use of QI methods facilitate or impede PHCP co-creation?*

The data showed Dialogue, Access, Reflexivity, and Transparency (DART) did then increase the quality of interactions between the public and HCPs, and QI methods could facilitate DART. In contexts where QI methods were already used, they offered a structure that brought together the public and HCPs to improve healthcare. These methods initiated dialogue between public and HCP co-creators, provided access to information about the improvement initiatives, and therefore enabled reflexivity and transparency.

Crucially, public co-creators needed to be trained in QI methods to optimise their ability to lead healthcare improvements in contexts where these methods were used. Some organisations did not feel this was necessary, and indeed there was no evidence that a lack of awareness of QI methods hindered public partners' ability to shape healthcare improvements. However, the public partners who led healthcare improvement needed knowledge about QI methods to validate their position and this enabled them to be co-creators rather than spectators. Supportive structural contexts were necessary to enable public to acquire the necessary skills to become meaningful QI leaders.

However, this chapter also cautioned that the use of QI methods can impede PHCP co-creation. A lack of resources or commitment to QI could enforce tokenistic public involvement. The use of QI methods took time and required a level of confidence and comfort about how the methods would be used and what they aimed to achieve. This meant it could be a new way of working for both HCP and public partners. Public partners were not always included when improvement initiatives used QI methods. Some HCPs did not feel public partners needed to know about QI methods. Other situations demonstrated an uncertainty about public roles when QI methods such as process maps were being adapted and used to map speculative healthcare situations. Additionally, not all QI methods were seen as appropriate for all forms of co-creation, particularly coproduced improvement initiatives or those in the community setting. The use of QI methods could cause tension between the public, HCPs, and organisations that mandated this way of working in coproduced initiatives. Interestingly, the data showed maintaining DART between the public, HCPs, and surrounding QI support systems could alleviate this tension.

Some situations, therefore, challenged the concept that QI methods could be applied with fidelity, highlighting situations where their use was ‘good enough’. That is, QI methods, such as PDSA cycles, were used to plan and test interventions aimed at improving co-creation but were not documented. In such situations, they did appear to enable demonstrable improvements to co-creation, and for healthcare improvement. Further research on the use of QI methods for formative evaluation of co-creation and the extent to which the methods may facilitate or impede coproduced improvement initiatives would be useful. It is stated that patient, service users, and carers should be central to organisational QI efforts[147]. Guidance is created to support public involvement in healthcare yet has limited transferability[190]. The further research proposed could provide useful insight into whether methods such as the driver diagram and PDSA cycle models in sub-section 7.3.2 could provide transferable approaches to support planning and assessment of co-creation.

This chapter makes original theoretical contributions by providing the first exploration of the relationship between DART and co-creation interactions in healthcare improvement. This exploration has made explicit DART as sub-processes that facilitate co-creation interactions between the public and HCPs. There were examples of QI methods facilitating DART between the public and HCPs, and influencing PHCP interactions in and with wider organisational contexts. PDSA cycles, for example, established a way of working that highlighted all components of DART and achieved more transformative PHCP interactions. Nevertheless, these interactions between the public and HCPs were also influenced by their positions and interactions with wider systems. Specific QI methods could challenge interactions between the public and HCPs in improvement teams and the wider organisational structures, although this tension initiated dialogue. Therefore, presence of *all* DART components facilitated more transformative PHCP co-creation. Further research should explore whether some DART components hold more weight for transformative interactions between the public and HCPs, and with the wider context.

The analysis contributes empirically to three broad literatures. Firstly, it enhances the business literature and tests the use of DART as a middle-range theory to improve PHCP co-creation in healthcare improvement. By introducing this middle-range theory, it offers a potential explanation and means to improve PHCP co-creation. It, therefore, contributes to the public involvement literature and responds to calls to study how we realise PI in healthcare settings[74,240]. In doing so, it provides tangible solutions that co-creators could use, such as driver diagram and PDSA models, to improve how the public and HCPs work together for service change. Finally, it adds to the Improvement Science literature by providing a novel exploration and explanation of why QI methods enable or impede PHCP co-creation. Specifically, these findings highlight the relationship between QI methods and DART.

The next chapter will bring together all the empirical findings and expand on the key empirical and theoretical contributions this thesis has made.

8. Discussion

This final chapter presents the main thesis findings. It highlights the key empirical and theoretical contributions this research makes to the knowledge base on public-healthcare professional (PHCP) partnerships in, and for, healthcare improvement.

This section revisits the gaps in the knowledge base that this research aimed to tackle and summarises the main findings from this thesis. It provides an overview of the factors that optimise co-creation which may be of particular use to public and HPC practitioners of this way of working. It presents an overview of the empirical and theoretical contributions this study makes. In particular, this section expands on four main empirical contributions that position PHCP co-creation as an experiential process, describe the value of co-creation, identify and describe facilitative practises for co-creation in healthcare improvement, and present roles for optimal co-creation. It then describes the theoretical contributions of this research and presents the intersection of healthcare improvement and PHCP co-creation, expands value co-creation as an explanatory theory to improve PHCP partnerships, and adds to the debate about the impact of co-creation. When describing these contributions, this section synthesises the findings and shows how this work relates to the wider body of research. The chapter then summarises the impact of this research, reflects on study design and limitations, and suggests areas for further research. Finally, this thesis concludes by presenting recommendations for practitioners and policy-makers.

8.1 Revisiting the gaps and associated research questions

This is a study of PHCP partnerships as approaches to achieve service change. It explores these partnerships in six organisations that encouraged and facilitated PHCP working to improve healthcare. Additionally, this research investigates experiences of PHCP working from seven individuals who provided relevant and interesting insight from varied experiences, rather than through focused case studies.

The literature review in Chapter 2 highlighted four key areas for further research of PHCP co-creation. Value co-creation had been proposed as a lens to optimise partnerships, enabling them to realise value and to enable the public to shape healthcare[76,278]. However, exploring value co-creation of PHCP partnerships for service change prospectively, was a notable gap. This gave rise to the overarching research question:

1. *How can value be realised through public-healthcare professional co-creation for service improvement?*

Value co-creation is a large and growing field. Ramaswamy and various colleagues' contribution positions co-creation as an interactional process[88] which aligns to how some position PHCP partnerships[96,283]. The literature on PHCP partnerships in healthcare improvement has focused on the role or impact of public partners. Therefore, the first sub-question aimed to make explicit this interactional process between PHCP partners and asked:

a. *What co-creation interactions occur between the public and HCPs in improvement initiatives?*

The third gap relates to the ongoing debate about how to assess the impact of PHCP partnerships. Assessing this impact is deemed necessary[350] but difficult[23]. Value has been suggested as a potential way of "rethinking impact assessment"[77]. Yet there has been no prospective exploration of the value of PHCP partnerships. The second sub-question aimed to provide this prospective examination to answer:

b. *What value is achieved through PHCP co-creation, and why is it deemed value?*

There remains scant literature exploring how and why the use of QI methods influence PHCP co-creation. The literature that does exist explores this through single organisations or case studies[113,114]. Therefore, this inquiry uses multiple case studies across various organisations to answer a fourth gap with the final sub-question:

c. *How and why does the use of QI methods facilitate or impede PHCP co-creation?*

These questions were addressed through the findings in chapters 4-7.

8.2 Optimising PHCP co-creation to realise value

Data from the cases and individuals in this study (Chapter 4-7) provide evidence for specific approaches that optimise PHCP co-creation thus realising value from this way of working. The models of co-creation outlined in this research demonstrate different approaches to how the public and HCP worked together for service improvement. I was able to find evidence of effective examples of co-creation including public partners' leading improvements (4.2.3;4.2.4), the public and HCP improving healthcare organisations processes and outcomes

(7.1.2), and PHCP co-creation being central to new models of care (6.1.3; 6.2.3). These examples demonstrated co-creation was optimised by three factors: **'necessary conditions', 'behaviours and principles',** and **'supportive practices'**. 'Necessary conditions' were largely the contextual provisions needed to optimise co-creation, 'behaviours and principles' were that which individual co-creators should embody, and 'supportive practices' facilitated a process of co-creation. A combination of these factors facilitated "high-quality interactions"[82,89] between the public and HCPs. In the design of service improvement all three factors should be recognised and implemented to create these interactions which appear crucial for successful and meaningful co-creation that realises value[82,88].

My research found these factors facilitated effective co-creation experiences between the public and HCPs that were more likely to realise value for the people involved, the related organisations, and the wider health, care, and improvement contexts (6.1). This section describes the necessary conditions, behaviours and principles, and supportive practices of effective co-creation experiences that led to the realisation of value in PHCP working.

8.2.1 Necessary conditions

Wider commitment to PHCP co-creation

Wider commitment to PHCP co-creation was important to ensure this way of working was meaningful and influential.

This wider commitment could come from strategically placed individuals, within or outside of organisations, who brought varied networks and relationships, knowledges, and influence. The process of co-creation and the influence it realised was, therefore, strengthened by what these individuals brought with them. This study demonstrated wider commitment to co-creation within an organisational setting was particularly necessary for initiatives that aimed to carry out improvements within that context. There needed to be a balance between buy-in from senior HCPs, and strategically placed individuals throughout the organisation, who practiced or championed co-creation. The presence of public partners or community members, and the process of them working with HCPs, could realise wider commitment to continue co-creation, especially when it was seen to realise value. Public partners or community members could additionally help realise wider commitment directly through the relationships, knowledges, and influence they brought.

Individuals who want to optimise PHCP co-creation should consider what they aim to achieve, and articulate the specificities of the wider commitment that could help realise this. This articulation calls for reflection of the context surrounding this way of working, including assessing why co-creation would be deemed of value (pg.252), and understanding the scope of the improvements being made. Such reflections can inform the strategically placed individuals that are needed, and clarify where they should be situated to optimise this way of working.

A culture of transparency

A culture of transparency between people within and outside of organisations was crucial to embed and optimise PHCP co-creation.

This study demonstrated a culture of transparency facilitated co-creation by providing an accurate understanding of health and care for all co-creators. Such cultures encouraged transparency about people's experiences and outcomes through data that enabled both public and HCP co-creators to specify the areas for improvement. Transparency about organisations' structures and processes was important to open up spaces that could otherwise exclude people from outside of organisations who were crucial to the co-creation process. This transparency supports public co-creators to understand how, and to what extent, they could influence improvement.

A culture of transparency should be created to optimise PHCP co-creation. This could include having systems in place to enable co-creators to understand both processes and outcomes. Transparency means being open about the bad and the good ways of working, the problems and issues to be addressed, and the inner workings of the organisation. Such openness may be initially uncomfortable, but was reported in this study to have subsequent benefits.

Being Flexible and Responsive

Meaningful and impactful PHCP co-creation for healthcare improvement was facilitated by flexible and responsive working that adapted to evolving situations and needs.

PHCP co-creation for healthcare improvement required flexibility and responsiveness, rather than rigidly focusing on achieving a predetermined goal through preordained processes. Successful co-creation responded to situations or needs that could arise in the wider contexts, including those which were urgent or previously unknown, and mattered to public or HCP co-creators. Flexible and responsive PHCP working meant adapting how the public and HCPs worked together, the approaches they used, and the roles they played to respond as needed.

People aiming to optimise PHCP co-creation should allocate some space, time, and resources for iterative, flexible working that is responsive to adapting needs. This could include adapting the roles and responsibilities of public and HCP co-creators (pg.242).

Purposefully designed spaces to bring people together

Purposefully designed spaces were important to bring together diverse groups of people who may still be learning how to work together.

Purposefully designed spaces went beyond being well-planned surroundings and included processes within these environments that engineered interactions between, and among, the public and HCPs. These processes deliberately enhanced spaces to facilitate collaboration between people from different backgrounds, who had diverse skills and experiences. The nuanced design of these spaces varied, and successful examples enabled people to connect with each other because they occurred regularly, were focused on a specific purpose, or both. Successful connections could be engineered by placing specific people in the right roles. Public co-creators could, for example, facilitate or lead improvement-focused or learning spaces. This could enable HCPs, who had never worked with the public as co-creators, to experience the potential roles public partners could play.

People aiming to optimise PHCP co-creation should give careful consideration to the design of spaces and the embedded processes, which deliberately bring people together to advance health and care improvement.

8.2.2 Behaviours and principles

Commitment to improve health and care

Successful examples of PHCP co-creation demonstrated co-creators needed to be committed to improve health and care.

Commitment to improve health and care strengthened PHCP co-creation by providing a sense of purpose, and could create cohesion for people who may not have previously worked together. This commitment provided a focus for the co-creation activity, and an overarching purpose, which could help assess the impact or influence that co-creation was achieving.

Commitment to improve health and care should be an essential requirement when recruiting public or HCP co-creators to the improvement initiative to optimise PHCP co-creation. Regular dialogue between the co-creators can assess whether they feel the initiative is realising the desired health and care improvements.

Motivation to work and learn together

Motivation to work and learn together among both public and HCP co-creators could optimise meaningful PHCP co-creation.

Such motivation enabled co-creators to form productive and evolving relationships. These relationships were crucial to how they worked and learned together. This, in turn, enabled the public and HCP co-creators to strengthen the co-creation process, for example, by working through tension that may arise.

Regular reflection on how public and HCP co-creators are working and learning together is more likely to lead to productive relationships that realise value. Public and HCP co-creators should be positioned as valid contributors who all have a responsibility to shape these productive working and learning relationships, establishing an equal and equitable partnership.

Ensure accessibility and inclusivity

Accessible and inclusive ways of working enabled individuals from different backgrounds, with varied experiences, and skills to position themselves as equals in their roles as co-creators.

An accessible process was more likely to enable effective PHCP co-creation. This comprised of ensuring accessible spaces and processes were used or created that enabled all co-creators to be included to improve healthcare. For example, accessible language without jargon enabled everyone to understand what was being said and supported people to be equal and active co-creators. Accessible PHCP co-creation could attract new co-creators with useful skills and experiences and this reduced the likelihood of exclusive groups forming, as demonstrated in the organisational case studies. This accessibility included people who had previously been excluded from healthcare improvement, health and care contexts, or this collaborative way of working.

Accessibility and inclusivity are crucial and interrelated factors that must be embedded to optimise PHCP co-creation and enable people to become active co-creators. This includes through the design of flexible processes that are adapted for people's various needs.

Value experience and experiences

The public and HCPs brought with them a range of experiences, and also gained additional experience through the activities they undertook during the co-creation process. This process of development enhanced this way of working, and increased the likelihood that it was an effective component to realise healthcare improvement.

The experiences that co-creators brought with them, or gained through the co-creation process, influenced how they navigated this way of working and the roles they played. Previous experiences included living with or caring for people with health conditions, using, or working in, health and care services (or both), professional experiences, and being part of specific communities. The experience of working together to realise healthcare improvement enabled public partners in particular to build influential relationships for service change. They learned how to navigate the surrounding contexts effectively, gain more comprehensive understanding, and build confidence to assert a more active and influential role. Experience was strengthened by the interactions that people had throughout the co-creation process, with other co-creators, or the surrounding contexts.

It is important to value the experiences that co-creators bring with them and equally those that they gain through the co-creation process, to optimise PHCP co-creation. Crucially, people and their experiences must be recognised, valued, and retained rather than being viewed as replaceable.

8.2.3 Supportive practices

Build relationships

Successful and meaningful co-creation centred on co-creators who connected as people and built effective relationships.

There was a fundamental relational aspect to PHCP co-creation which influenced the success of this way of working. The public and HCPs needed time to connect as people, learn about each other, their lives, skills, and experiences to understand what they could bring to the co-creation process, and how they could work together. Successful examples of PHCP co-creation demonstrated active relationship building was crucial to optimise this way of working, including through informal interactions that took place alongside the core co-creation activities. These formal and informal interactions provided ways to demonstrate the co-creators valued each other.

Building meaningful relationships takes effort, and while it can happen during the co-creation process, it is likely to need more specific actions. Therefore, people who aim to optimise co-creation should factor in appropriate time and approaches for public and HCP co-creators to connect as people, going beyond labels or roles.

Embed reflective practice

Embedding reflective practice enabled public and HCP co-creators to regularly learn and improve co-creation, and optimise the influence this way of working had on healthcare improvement.

The data demonstrated reflection by public and HCP co-creators provided collaborative learning that could inform iterative changes to improve co-creation practice. Regular, collaborative reflection helped co-creators and other key stakeholders understand what worked, and strengthen collaborative practice for healthcare improvement. Additionally, such reflection informed experimental iterations of the co-creation process. The continuous learning enabled through this reflective practice strengthened relationships by facilitating dialogue and transparency, and through co-creators feeling they were heard and their input valued.

People who aim to optimise PHCP co-creation should embed and facilitate regular, collaborative reflection that can provide learning to inform adaptations to the co-creation process. Such reflection should support formative assessment of the influence and impact of co-creation.

Encourage constructive critique

PHCP co-creation was optimised through constructive critique of the co-creation process, and of surrounding health and care contexts. Such critique was productive because it aimed to enhance the improvements or the co-creation process, while enabling co-creators to raise issues and experiences that they felt were important.

In some contexts, constructive critique was embraced and seen as valuable for learning and evolving co-creation and healthcare improvement. Such contexts positioned this critique as useful data to influence and improve ways of working and health and care, even though it may have been uncomfortable or lead to conflict. Organisations such as Deep, Ekta, Tayjan, and Jinja established processes and systems to encourage and support people to critique the organisations, and PHCP working. This analysis demonstrated trusted and strategically placed individuals within the initiatives or organisations were important to elicit and facilitate critique from public and HCP co-creators.

People aiming to optimise PHCP co-creation should create safe spaces and embed facilitative processes to encourage constructive critique and challenge. It is important to position such critique as useful data for learning and improving, and an important, regular measure of how the public and HCPs are working together to improve health and care.

Adapt and use existing tools and approaches

PHCP co-creation could be optimised by adapting and using existing tools and approaches that were routine in the contexts in which co-creation and related healthcare improvement activities occurred.

The contexts surrounding PHCP co-creation were replete with tools and approaches that were used for co-creation or could be adapted to facilitate this way of working. These tools and approaches provided technical methods to tackle healthcare improvement, and could facilitate and strengthen relationships among co-creators. For example, existing tools could embed methods that built interactions and connections between the public and HCPs, and between PHCP and the contexts influencing healthcare improvement. Public and HCP co-creators were more likely to use such tools and approaches when they felt they optimised or continued what people were already doing, rather than creating new or additional work.

It is important to understand the tools and approaches that exist and assess how these can be adapted and used to optimise PHCP co-creation. The focus should be to strengthen the co-creation process rather than diverting energies and resources to create novel tools or work.

This next sub-section will summarise the other main findings in this thesis.

8.3 Summary of other main findings

The other main findings in this thesis were that the value of PHCP partnerships for service change could be realised through a combination of roles for individuals and supportive structures and platforms (4;5). These could then facilitate the multiple, varied and dynamic PHCP interactions that take place in improvement initiatives. Higher-quality interactions were facilitated by Dialogue, Access, Reflexivity and Transparency (DART)[86,109] (5; 7). The use of QI methods could foster DART between the public and HCPs, thereby enabling higher quality interactions as shown in Chapter 7. Such interactions were more likely to realise value for individuals, organisations, and society (6.1). Examples of such value included improved awareness of healthcare systems for individuals, organisational effectiveness, and new ways of delivering care (6). While this value was unique to the specific examples of co-creation captured, the insight into why value was deemed such could be useful for other PHCP partnerships. Ultimately value was more likely to be recognised by those beyond the improvement initiatives when it was tangible and visible. Experiential value was however, deemed important to the PHCP co-creators themselves.

These findings make theoretical and empirical contributions to the healthcare improvement, public involvement, and value co-creation fields, and could enable more meaningful PHCP co-creation (Table 15). Meaningful in this sense means realising synergistic co-creation more likely to achieve improved healthcare. This thesis could inform improved practice or different research approaches that position the public and HCPs as active co-creators.

Continued overleaf.

Table 15: Thesis Contributions

	Healthcare improvement	**Public Involvement**	**Value co-creation**
Empirical contributions	Describes how PHCP partnerships can realise value for healthcare improvement	Provides detailed cases of various PHCP partnerships in healthcare improvement initiatives	Describes and defines Dialogue, Access, Reflexivity, and Transparency between the public and HCPs
	Explains how specifically designed healthcare improvement contexts can optimise PHCP partnerships	Explains eight specific roles that public and HCPs can play to influence healthcare improvement	Describes how healthcare improvement contexts create 'engagement platforms' that can facilitate PHCP partnerships
	Demonstrates the use of QI methods can facilitate high-quality interactions between people	Positions PHCP co-creation as an interactional process thereby aligning with Staley and Baron (2019) and Gibson et al. (2017)	Creates four new roles that co-creators played thereby expanding Nambisan and Nambisan's (2014) contribution
Theoretical contributions	Demonstrates the potential of Ramaswamy and colleagues' (2010, 2014) theory on creating engagement platforms to enhance PHCP involvement for healthcare improvement	Responds to McKevitt et al.'s (2018) call to explore how value is produced by proposing the Experiential-Tangible Value model	Demonstrates value co-creation is a useful middle-range theory to explain PHCP partnerships
	Builds on Ramaswamy and colleagues' (2004, 2010, 2014) work and presents the first empirical exploration of Dialogue, Access, Reflexivity and Transparency to explain how to engage people to improve healthcare systems	Builds knowledge on how the interplay between individual co-creators and wider supportive structures can increase the effectiveness of co-creation	Expands the interactional nature of Nambisan and Nambisan's (2014) roles for citizens in public sector co-creation
	Substantiated the use of DART to explain how and why the use of QI methods can engage public and HCPs for healthcare improvement	Demonstrates value co-creation as an explanatory theory to improve how public and HCPs work together	Evidences value co-creation can address power dynamics that impede healthcare co-creation

The four main empirical and three main theoretical contributions that this thesis makes will be discussed.

8.4 Empirical contributions

This thesis makes four main empirical contributions:

1. Positions PHCP co-creation as an experiential process;
2. Describes the value of co-creation;
3. Identifies and describes facilitative practises for co-creation in healthcare improvement;
4. Presents roles for optimal co-creation.

1. Public-HCP co-creation as an experiential process

PHCP co-creation in healthcare improvement is an experiential process established through dynamic interactions, as evidenced through the four case studies within organisation Deep (5) and the six organisational case studies. Chapter 4 described how experiencing co-creation and realising value increased the likelihood of PHCP working together in future initiatives. Several examples throughout this research show that PHCP interactions, rather than only public or HCP involvement, were key to successful co-creation experiences. For example, public and HCP interactions led to staff in organisation Tayjan better understanding issues that prevented them from delivering higher quality healthcare. These initial interactions built relationships between the public and HCPs, establishing partnerships for healthcare improvement, and enabled them to find solutions that helped Tayjan deliver responsive healthcare. This is consistent with Prahalad and Ramaswamy's (2004) assertion that interactions are "the locus of value creation and value extraction"[260]. These interactions can shape co-creation experiences that lead to transformative change.

Co-creation experiences were formed by interactions that went beyond the public and HCPs. The case studies in Chapter 5 highlight dynamic and complex interactions influenced by non-human elements. PHCP interactions in initiative Jugat initially focused on exploring patient journeys of care at engagement events (5.7.2). Public participants mapped their journeys thereby providing a focus for their interactions with the other public and HCPs present. Later, the public and HCPs worked to shape and test an app that aimed to provide responsive patient information. For some, like Neena (Public), this improved her co-creation experience. She felt the app had real potential and it motivated her to continue to interact. However, this disengaged Inderjeet (Public) who was not as comfortable with the technology, and Dorothy (HCP) whose workload increased because of the app testing. Therefore, interactions with the same artefacts or processes may lead to different experiences for the individual co-creators.

Co-creation experiences were unique which may explain why the literature presents PHCP working as a variable practice. This aligns with evidence from healthcare research articulating the experiential nature of public-researcher working[96,106] and describing its dynamic interactions[90,283]. The added complexity comes because of the interactions between multiple actors, and with artefacts, systems and so forth[88,268]. Interactions between HCP team members in project Woke and the surrounding organisational systems impeded them engaging specific public (Chapter 5.4). Conversely, the medications document that they co-created facilitated interactions between the team members, and with individuals outside of the team and other organisations. This supports Staley and Barron's (2019) assertion that "involvement is evolutionary, in unpredictably progressing through a series of interrelated episodes of learning, rather than following a linear, fixed path."[96] Co-creation is then a personalised experience for each individual involved which increases the difficulty in managing the process.

Positioning co-creation as an experiential process is a useful way to address the implementation gap of PHCP working. This gap comprises HCPs and researchers knowing that the public 'should' be involved but struggling to meaningfully implement this way of working[21,22,24]. This is perpetuated by reinforcing traditional hierarchies where researchers' knowledge is prioritised above the public[22]. Evidence shows an absence of transparency and dialogue between HCPs and the public[24], and situations where they are not placed as reflexive partners[22] can undermine attempts to meaningfully work together. Experiencing co-creation may be a way to overcome situations where knowledge does not connect or lead to action[356,357]. Pfeffer and Sutton (1999) state "knowledge comes from doing and teaching others how"[357(p248)]. They emphasise learning by doing, through collaboration, by making mistakes, and reflecting on what has been done by measuring what matters[357]. Staley and Barron (2019) advance this for public involvement (PI) in research demonstrating learning occurs through the experience of people working together[96]. They explain it is difficult to plan how to work together when "researchers 'don't know what they don't know'"[96]. It is only through the experience of involving the public that researchers learn how to do it. This thesis has demonstrated the importance of reflective, experiential learning to advance PHCP co-creation in healthcare improvement, and evidenced this as an important part of its implementation. The DART model provides one way to explain the how-to of co-creation.

My empirical application of the DART model[82] found it explained productive PHCP interactions. This research confirmed Prahalad and Ramaswamy's (2004) assertion that DART are the "building blocks" of interactions between companies and customer[82], or in this case between the public and HCPs. Each component of the model was translated and successfully applied to explain PHCP working in healthcare and related organisations (4.2.2). DART makes explicit key characteristics in PHCP interactions that could be managed and provides a framework to facilitate quality interactions between the public and HCPs. The relationship between PHCP team members in Samaaj was strengthened through their equal partnership embedded through the coproduction of the initiative (5.5). The public and HCPs had equal access to information and the relevant stakeholders necessary to realise the initiative's aim to improve peer-led management of the chronic condition. Dialogue and reflexivity enabled initiatives Samaaj and organisation Deep to work through tension related to different work cultures. An example of this was Samaaj team members challenging the sustainability planning tool used by Deep (7.4.4). By discussing this and reflecting on potential solutions, Samaaj and Deep were able to inform the evolution of a new sustainability planning tool.

Interestingly, application of the DART model in such circumstances challenged the literature conceptualising value co-destruction. This literature describes value co-destruction as inevitable and inherent[100,358]. If value can be created, it can be destroyed. Both creation and destruction can occur rapidly[100]. However, examples such as dialogue and reflexivity between organisation Deep and initiative Samaaj demonstrated value co-destruction was not inevitable and could be averted. Potentially destructive conflict could become generative. This emphasised the potential of the DART model to elucidate complex ways of working such as PHCP co-creation.

The published literature describes the complex nature of public participation related to the various actors, processes, models, and underpinning philosophies that exist[73,108,205,233,359], with some positioning PI as a complex intervention[238]. Staley et al. (2014) state that PI is a complex social intervention, and its impact is influenced by an array of factors including surrounding contexts and mechanisms[108]. Existing sociological theories such as Delanda's reading of assemblage theory is another approach that could be useful for researchers or those interested in explaining PI as “a wide variety of wholes constructed from heterogeneous parts”[268(p3)]. These assemblages “emerge from the interactions between their parts”[267(p21)] and could describe the multiplicity of healthcare systems and relevant individuals who all come together[360]. Thus, assemblage theory could account for the complex and non-linear relations between PI and its components, and the social and interactional nature of PHCP working[88,108,205,361]. The exploration of assemblage theory for PI was beyond the scope of this research, but offers interesting potential for further research.

My empirical application of the DART model[82,85,86] demonstrates one way to manage the complex nature of PHCP co-creation. Conceptual and theoretical models and typologies have attempted to describe or manage the complex array of PI contexts, approaches, and interactions[205,212,215,362–364], and aim to help those researching and practising PI. However, these models and typologies do not provide a tangible level of detail that enables practitioners and managers of PHCP working to improve their practice. Ocloo and Matthews (2016) argue these models can be narrow, stating “broader frameworks and methods of involvement should be used that offer better ways to share power with healthcare professionals”[23]. The DART model[82,85,86] provides a level of detail missing from other conceptual and theoretical frameworks that aim to manage PHCP interactions (4.2.2; 7.1.2). The model describes four interrelated components which influence PHCP working. The definitions of the components constructed through this thesis (Table 16) offers a way of acknowledging and managing power dynamics between public and HCP co-creators.

Continued overleaf.

Table 16 Definitions of DART for PHCP co-creation from my data

	How this manifested in PHCP co-creation (definitions based on data collected in this PhD, adapting Ramaswamy and Ozcan, 2014[86])
Dialogue	Dialogue between public and HCP enabled them to shape healthcare improvement. The public were often invited into healthcare and related settings and processes in which they may not otherwise be included.
Access	Both public and HCP partners gained information about healthcare experiences and processes. HCP and sometimes public would learn about and access tools and expertise that supported co-creation for healthcare improvement.
Reflexivity	Public and HCP would reflect on both the co-creation process and the proposed healthcare improvements, adapting these as needed. This was a strong characteristic in the six organisational case studies.
Transparency	Transparency of healthcare and related organisations and the purpose of co-creation, was necessary to enable both public and HCP to fully engage. This happened at varying levels.

2. The value of co-creation

My analysis demonstrated the individual, organisational, and societal value of PHCP co-creation in a range of healthcare improvement initiatives (Chapter 6.1). Co-creation could enable individuals to better manage health and care, through more personalised information on health conditions or more accurate understanding of the reality of healthcare practices and systems. Co-creation could improve organisational accountability and effectiveness, and build or strengthen relationships between organisations and their surrounding communities. This accountability and effectiveness could contribute to more responsive healthcare planning and delivery even for those not involved in the co-creation process. For example, Arundhati described co-creation breaking down the stigma held by HCPs of people with HIV, which led to more responsive healthcare design (7.2.3). The value realised for individuals, organisations, or society contributed towards realising more collaborative health and care management.

The lens applied in this study provided an understanding of the value of co-creation from those involved in the process. My study found the value of PHCP co-creation was the process, outputs, and outcomes of this way of working. There was evidence that "value is always uniquely, phenomenologically determined by the beneficiary"[257], but there were equally preconceived views of value determined by organisations and people external to the co-creation process. These preconceived views could influence what was deemed value (6.2) and why some co-creation activities were considered to bring value or be successful (5.5.5; 0; 0). The value of PHCP co-creation is therefore, complex and multifaceted, and required 'necessary conditions', 'behaviours and principles', and 'supportive practices'(8.2) that created high-quality interactions between co-creators[89]. Ramaswamy and colleagues' significant empirical evidence demonstrates the importance of high-quality interactions to value creation[82,85,86], and required a focus on creating personalised experiences[89]. My research demonstrated the public and HCPs personalised co-creation experiences can influence this way of working and the value it realises (4.1.5; 4.2; 5.4;5.7).

My study presented an analysis of value based on a qualitative assessment of benefits and costs. This analysis helped to frame and focus the value of co-creation based on the participants' reporting, or my own observations. It enabled me to extract benefits and costs from what they said or did. Attempts to code against McKevitt et al.'s (2018) three conceptual categories of value for involvement in major system change: agitation management; verification; and substantiation proved more difficult[77]. While there was evidence of these types of value, they did not fully explain all the value demonstrated in my study. Crucially, it is less likely that the public and HCPs in my research would define agitation management and verification, in particular, as the value that mattered to them. Agitation related to "managing actual or potential resistance or agitation"[77], and verification related to proactive PI that provided a mechanism to "anticipate and manage any dissent"[77] and verify the plans for the proposed changes to healthcare delivery[77]. Yet, my analysis has demonstrated 'agitation' can be generative (5.8.3) and there are, therefore, questions about for whom does managing this add value? In McKevitt's work, it appears this adds value for those leading major system change[77] potentially at the expense of the public. The examples in this thesis challenge verification being of value to those actively engaged in co-creation. Verification could perpetuate the culture that Isabella (Public) warned us about where co-creation could mean "a token patient… invited in so that a box can be ticked" (4.2.3). My analysis found value came not from verification, but from truly co-creating new or improved ways of delivering healthcare (pg.171). As Rohinton (Public) articulated so clearly, value for many of the co-creators in this research meant "as a result of a contribution I make, something changes and that one feels that either at the time, or later, that

that's a change for the better" (pg.173). Value in the examples in this thesis then, meant improving or challenging the status quo, when needed, to deliver something meaningful to the beneficiaries, including public co-creators, and patients.

Therefore, McKevitt et al. (2018) provide a useful starting point for explorations of value by pragmatically focusing on three types of value that may provide tangible examples. I agree with McKevitt et al. (2018) who suggest that these categories should be further, formatively tested[77]. This should include testing the acceptance of value being defined as agitation management; verification; and substantiation with public and HCP co-creators, refining the concepts as necessary. It may also be useful to explore the potential of providing a pragmatic tool for co-creation practitioners. Such a tool could assess the value of involvement but also provide data to optimise this way of working, and what it realises. This is important as this thesis found while value was a potentially useful way of assessing the benefits and costs of PHCP co-creation, it could be an equally nebulous term without clear definitions.

It was harder for participants in this research to articulate the 'costs' of co-creation. The costs found in this analysis (economic, emotional, extra work, physical costs to health, time) largely echoed Blackburn et al.'s (2018) financial and non-financial costs for individuals and organisations[365]. Their study of PI in primary care research found researchers had similar difficulty making explicit the costs of working with the public[365]. This challenge needs further consideration among calls from Samuel and Farsides (2018) to manage expectations of patients and public participants' journeys in genomics through reflection and balance of costs and benefits[24]. While an admirable goal, such exploration would need to be carefully considered and managed to present an accurate picture. Blackburn et al.'s (2018) cost and consequence framework may enable such consideration.

Any framework or approach must give the public and HCPs freedom to present the dichotomous nature of the value of co-creation. This was exemplified through the unique and interesting experience of Charlotte who stated co-creation had given her purpose and prevented her from taking her own life, yet it also adversely impacted her physical health (6.4). Charlotte's experience provides an important test case for frameworks or approaches to explore whether benefits outweigh the costs and provide a more nuanced articulation of contexts and unintended consequences of co-creation.

My research provided an understanding of co-creation that complements other assessments of the value of this way of working, and sits alongside research evidencing a demonstrable return on investment of PI[246]. The value co-creation (VCC) framework was chosen as it provided a way to uncover the design of PHCP co-creation and explain how to optimise this process to realise value. However, some people may feel this assessment provides limited information to inform a quantifiable understanding of the tangible resources that need to be allocated to realise high-quality co-creation. The VCC framework as applied in my research, cannot demonstrate a financial investment in PHCP co-creation will lead to a return. It cannot then, inform organisation budgets by making explicit the resources that should be spent on PHCP co-creation to realise value from this way of working. Such information about resources required may be important because cuts in spending including in health are likely to have resulted in widening inequalities[366], but also have come with the promise to optimise "taxpayers' investment"[26].

The VCC framework offers potential to inform healthcare design and delivery because it sits among alternative explorations of value and human action[367,368]. Such explorations seek alternative approaches for transformative action to improve wellbeing (6.1), tackle inequalities (4.3.6)[366,369], and realise health equity(6.2.3)[370] so people and environments thrive rather than simply survive[368]. The meanings of 'value' and understanding of co-creation practices that have emerged through this thesis offer useful insight for emerging models of health and social care including anchor institutions[26,371]. My analysis can inform the anchor institutions reimaging of how they will work with local communities, and crucially help create meaningful interactions to increase the likelihood of realising value.

3. Facilitative practices and co-creation in healthcare improvement

My research found PHCP co-creation was still not considered normal practice, especially by HCP co-creators. The data showed clinical HCPs in particular were likely to conclude that working with the public as partners was not widespread practice among their peers (4.1.3). The NHS in particular, was seen to be target-driven rather than people-focused and participants stated this impeded co-creation. Existing structures, especially in traditional healthcare settings such as hospitals or GP surgeries, could regulate how individuals behaved and define their roles. The NHS, for example, was thought to create professional boundaries that emphasised single identities and, therefore, expected patients to be solely patients. Some HCPs therefore felt patients should be subservient or only bring with them experiences of healthcare rather than their professional experiences as researchers or industry specialists (4.1.4). These views could influence how HCPs engaged with the public and reinforce hierarchies between the co-creators, and present barriers to PHCP co-creation including impeding the influence of public partners.

The analysis supports ongoing narratives describing the roles of structures and contexts in influencing how the public, in particular, shape healthcare planning and delivery[59,60,91,196]. It also supports Martin's (2008) findings that HCPs "ascribed a certain degree of representative legitimacy to involved users, on the basis of their laity (vis-à-vis clinical expertise) and their patient-hood"[196]. My research is over ten years after Martin's, and yet finds similar issues around accepted and expected public behaviours, and suggests that inherent power dynamics have not changed. Indeed, Beresford (2019) points out that structures for participation are inherited and bolster dominant ideologies and interests of the powerful, rather than those who may be in more need[60]. Individuals working in healthcare systems may, therefore, view "invited participation", where public are invited to service change, as more desirable[59]. This emphasises a need to create structures that facilitate co-creation by challenging the status quo.

Specifically designed healthcare improvement contexts facilitated PHCP co-creation, as demonstrated by the six organisational case studies (4.1.6,5.2.1,7). Healthcare improvement initiatives created facilitative systems and practices to support PHCP co-creation even if this was countercultural in the overall organisational context (4.1.1,5,7). Organisations such as Deep, Ekta, and Tayjan had created similar cultures and established comparable processes. They emphasised and facilitated collaborative approaches to QI that brought together public and HCPs as the organisation's modus operandi. They trained public co-creators alongside HCPs, enabling and supporting the public to lead QI. The organisations designed and facilitated platforms to engage public and HCPs especially through learning spaces. These examples, from different QI organisations, corroborated research demonstrating the potential of QI cultures to facilitate PHCP working. Jabbal (2017) for example, found such cultures could reinforce patient-focused and people-focused healthcare improvement and a participant in their research articulated the need to explore how the public can lead QI[147]. Renedo et al.'s (2014) research into PHCP working in QI organisations and cultures described four practices that facilitated co-creation: 1) the commitment to non-hierarchical collaboration, 2) organisational staff modelling behaviours that facilitate co-creation, 3) iterative cycles of doing and learning, 4) regular data collection and reflection facilitated by QI methods[114].

Yet, even with these structures the novelty of both the improvement sphere and co-creation practice sometimes created challenges specifically of how HCPs engaged with the related spaces or processes. The novelty of improvement and co-creation compounded HCP discomfort and uncertainty of the roles public co-creators would play (C4, C5). There were examples where HCPs did not invite public team members to spaces that aimed to facilitate collaborative learning and practice focused on improvement (C4, 5). Similarly, HCPs themselves would disengage from PHCP co-creation when it occurred in more neutral, non-healthcare settings (C5).

Findings from Simeen Mahmud's (2007) analysis of spaces for participation in health systems in rural Bangladesh resonate with this data, suggestive of a more generalised issue:

> "simply creating spaces will not lead to participation if people are not also sufficiently motivated to engage in them, but participation without engagement with providers may not be adequate to bring about the anticipated change in provider attitudes and behaviour vis-à-vis citizens"[3(p55)].

Other research by Brosnan (2013) provide solutions by offering an explanatory model of how power dynamics manifest and relate to levels of PI in healthcare[201]. In this paper, Brosnan describes how participants can navigate such spaces to make them more participatory rather than relying on being invited into them[201].

My findings add to this literature by applying a different theory to explain how to design and create such spaces for engagement. Ramaswamy and colleagues' platforms for engagement[85,86,88] provide a micro-level explanation of how such spaces can be designed. My analysis from PHCP co-creation in healthcare improvement are consistent with Ramaswamy and colleagues' research and revealed engagement platforms existed that enabled and facilitated co-creation[85,86,88]. The contexts I studied support Ramaswamy and Ozcan's (2014) findings that these platforms enabled "individuals [to] exercise their agency in creating value together"[86(p17)]. My research demonstrates these platforms were entities that enabled the public and HCPs to actively come together and interact with each other to improve healthcare. The actual platforms differed but all fostered some form of interactions between the public and HCPs, and with the wider healthcare systems and processes (5). The limitations of Ramaswamy and Ozcan's APPI theory[86,88] is described later (sub-section 8.5 part 2), but this analysis has found some form of engagement platforms existed in the improvement initiatives explored. These platforms were purposefully designed[86] and deliberately thought out spaces and processes, rather than randomly or naturally occurring. The platforms enabled and enhanced co-creation and could support productive co-creation experiences. Crucially, these platforms supported co-creation even when this way of working was counterculture to the wider organisational norms.

4. Roles for effective co-creation

My research highlights that uncertainty about public and HCP roles could impede meaningful co-creation and the value realised through this way of working. Observations from initiative Connect highlighted a willingness of HCPs like Rita to work with the public to make responsive healthcare improvements. This led to her making meaningful efforts to work with Max (Public) to shape healthcare improvements. Yet, uncertainty about Max's role during a theoretical process mapping session led to less meaningful, less impactful co-creation. Rita and Max soon stopped working together as co-creators. Similarly, HCP uncertainty about their roles in improvement and co-creation could prevent them from inviting potential public partners. The Ekta case study (4.1.6) described how the organisation created learning spaces for improvement initiatives and encouraged the teams to bring public partners. Yet the HCP-led improvement initiative teams rarely brought public partners to the learning spaces. Uncertainty about their own roles in the improvement process may make it difficult to understand potential roles for public partners.

My data corroborates O'Shea et al.'s (2016) explorations showing a lack of clarity about public roles in CCGs[372]. My findings show that this uncertainty is not unique to CCGs and it exists across a wide range of healthcare settings. Other literature, largely pre-dating O'Shea et al.'s, highlights the importance of the public having considered and full roles in quality improvement teams[48,78,284]. Yet there is an absence in the literature of examples of potential roles, which can perpetuate the implementation gap between the public and HCPs being motivated to work together, but being unsure how to do so.

Nambisan and Nambisan's (2014) proposition that citizens can be Explorers, Ideators, Designers, and Diffusers in co-creation provided examples of potential roles that could apply to PHCP partnerships[279]. The results from my thesis demonstrate that these four concepts were all evident within the case studies. Public co-creators did play these roles in the improvement initiatives investigated, though these specific terms were not used by public or HCP participants in this study. There were rich data in my findings, positioning public partners as designers of healthcare solutions (4.1.6,4.2.34.2.44.3.4), and more active public co-creators could be diffusers of new innovations or ways of delivering healthcare (4.1.6.,5.5,5.4). However, there were examples of organisations less willing to enable public co-creators to fully conceptualise problems (explorers) and conceptualise solutions (ideators). Public partners may be invited in after problems had been conceptualised or their solutions may not be taken on board. This was most evident in the example where a CCG rejected Chris (Public) and colleagues' offer to co-produce its quality report. Chris and his colleagues had established relationships with HCPs through seemingly meaningful co-creation at the CCG. Yet these relationships did not provide them with the autonomy necessary to make tangible improvements that mattered to patients within the existing healthcare structure.

Such examples challenge the focus on public roles in existing literature. Creating roles for the public does not always lead to them being able to increase their influence on healthcare improvement. These roles reinforce PI within "invited participation" as discussed earlier. It can limit the potential of public partners to influence responsive healthcare improvements. My findings demonstrated more complex relationships between the public, HCPs, and wider contexts influenced how meaningful co-creation was, and what the individuals involved could achieve. My work, therefore, corroborates Batalden et al.'s (2015) assertion that healthcare is a service co-created by these actors and the relationships they form.

Indeed, my analysis using Nambisan and Nambisan's (2014) four roles for citizens[279] showed HCPs also need to actively adopt these roles. The public and HCPs should, therefore, be co-Explorers, co-Ideators, co-Designers and co-Diffusers. Structured approaches such as Experience-based Co-design (EBCD), therefore, are useful examples of ways that can provide both public and HCPs with active roles[49]. Donetto et al.'s (2014) review of EBCD projects revealed this method could foster energy and create a cohesion and collaboration among public and HCP team members[49]. However, this review also emphasised the difficulty HCPs faced in transferring "between their 'expert' and 'decision-maker' role to becoming a partner and colleague"[49]. This highlights the importance of the 'co' and a managed interactional process that enables HCPs to be active participants. It also stresses the difficulty in realising this, even with a structured facilitated process such as EBCD. This again, highlights the complexity of PHCP relationships.

My findings found an additional four roles for co-creators, Advocates, Gatekeepers, Connectors, and Benefactors, that helped make explicit the relationships between public and HCPs in improvement initiatives. Advocates and Gatekeepers were largely HCPs, although public Gatekeepers did exist (4.3.2), and these roles provided examples of tangible positions HCPs played. However, these roles may perpetuate an environment more likely to produce "co-opted relationship[s]"[91]. In such relationships, the public slot into roles or spaces created for them and defined by researchers, rather than being an inherent part of co-creation from the outset[91]. This could happen if HCP Advocates and Gatekeepers structured public partners' participation through shaping the opportunities available. This could include providing support and training to reinforce specific ways of thinking or being. Green and Johns (2019) highlight the positivist paradigm perpetuates hierarchy of evidence and knowledge that become a way of public partners being co-opted and coerced into specific ways of behaving and participating[91]. As mentioned in Chapter 3, the drive to promote evidence-based medicine is seen to dominate healthcare practise[332–335] and, therefore, could have been an influencing factor in this research.

The ethics around the public as Benefactors for healthcare initiatives were not mentioned in the findings. However, there are questions about whether the public should be supplementing and providing healthcare services, as this could perpetuate inequalities in both healthcare and co-creation. It could also set a dangerous precedent that enables those who can afford to, to supplement healthcare that matters to them but then excludes services of more relevance to others.

8.5 Theoretical contributions

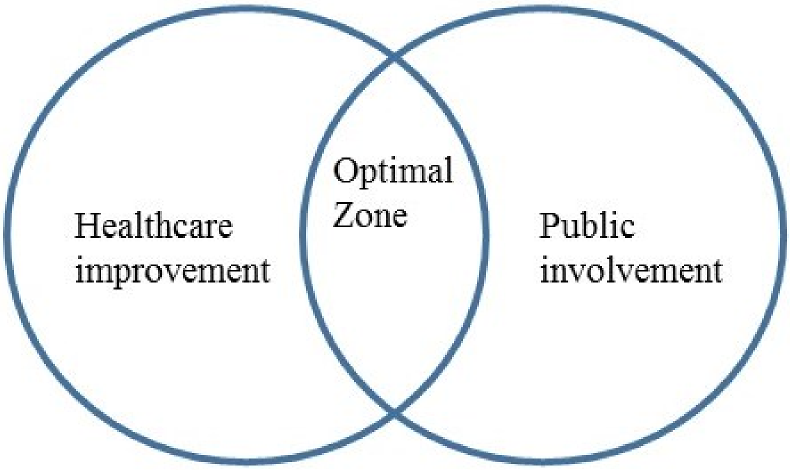
This thesis makes three key theoretical contributions:

1. Presents the intersection of healthcare improvement and PHCP co-creation
2. Expands value co-creation as an explanatory theory to improve PHCP partnerships
3. Adds to the debate about the impact of co-creation

1. Optimising the intersection of healthcare improvement and PHCP co-creation

This thesis argues there is a zone between healthcare improvement and PHCP co-creation that could optimise both fields (Figure 24). In this space, the public are seen as integral to healthcare improvement, and improvement methods can provide a solution to facilitate how people work together. My findings demonstrated this optimal zone through co-creation improving healthcare improvement (Chapters 4;5;6), and the use of QI methods improving co-creation (Chapter 7.3).

Figure 24: The optimal zone for co-creation



Co-creation improving healthcare improvement.

My findings showed public partners could improve healthcare improvement by initiating changes responsive to patient/public needs, or co-creating healthcare innovations (Chapter 6). This corroborates the growing literature highlighting the public provide alternative perspectives to HCPs that can initiate healthcare improvement[361,373], and their involvement can be a core part of the co-creation of innovations[87,374].

Positioning healthcare improvement as a collaborative effort[131,155] provided a conducive environment for PHCP partnerships[181,375]. However, my analysis found there could be challenges to the public and HCPs working together in the improvement initiatives, in line with research by Greene et al. (2018)[57]. The process of the public and HCPs working together could be alien for both, leading to uncertainty about how it would manifest[57]. This way of working needs to be resourced and carefully managed[57,78]. Yet my findings corroborate participatory practices can be difficult to implement as outlined below. Glimmerveen et al. (2019) found difficulties stemmed from “a need to reconcile: lay and professional knowledge; local alignment and central coordination; citizens’ diversity…; the concerns of citizens and organizational actors”[376].

My findings show a difficulty in participatory working came from the physical and mental distance between this way of working and daily tasks. Daily priorities for HCPs included delivering patient care, and for the public it included careers, hobbies, and other activities. Improving healthcare was then somewhat of a lesser priority. However, PHCP co-creation to improve healthcare was even further removed from people’s daily priorities. My findings suggest that co-creation was a sub-process for healthcare improvement and could be overlooked or forgotten.

The construal-level theory of psychological distance[377–379] could explain why this distance made it difficult to embed participatory approaches. Trope and Liberman (2010, 2012) explain how we respond to things is based on whether we experience them here and now or at a distance[377,378]. They specify four dimensions (temporal; spatial; social; and hypothetical) influence this distance[377]. Explaining this further, we may for example procrastinate if a deadline is in two months and work harder if it is in two days. We may feel differently about a meeting happening ‘here’ or elsewhere. We may behave differently with colleagues or with strangers. And we may think differently about healthcare improvements that are more or less hypothetical. These four dimensions at varying levels may have influenced how the public and HCPs positioned and navigated co-creation in line with other priorities.

This could explain why methods such as experience-based co-design (EBCD) can work well to bring people together for healthcare improvement. EBCD prioritises healthcare improvement around a structured approach[49] that makes it less theoretical. It brings together the public and HCPs around specific tasks and gives them specific roles[49,380]. The structured process, therefore, provides a way for the public to increase their influence on healthcare improvement[182]. This method bridged the social dimension of psychological distance. Yet EBCD could also be viewed as a slow, complicated process in which staff did not always engage[49].

QI methods to improve co-creation

Some public and HCPs used QI methods to improve co-creation practice and impact. This novel relationship between QI and co-creation does not appear to have been previously published. Both Ekta and Deep showed examples of using QI methods to assess the impact of co-creation (Chapter 7). Both organisations created driver diagrams to conceptualise the problem they aimed to tackle through co-creation. The driver diagrams were used to consider and articulate perceived potential solutions. This enabled PHCP co-creators to frame co-creation within the QI language used by their organisations. For Ekta in particular, the use of driver diagrams offered a way to create considered measures to monitor the impact of PHCP working. Deep used plan-do-study-act (PDSA) cycles to articulate and test interventions aimed to improve how PHCP worked together. Individuals planning the interventions would use the PDSA cycles to reflect on what happened. Additionally, they would reflect and document what changes they could make to encourage better co-creation through future PDSA cycles.

QI methods were used to increase the likelihood of successful PHCP working. Organisation Jinja described how working with communities led to, and required, different methods to improve healthcare. They used PDSA cycles to initiate and establish better working between the public and HCPs. Rather than using the cycles with fidelity, they used them to embed reflective, iterative practice. They tried to test interventions that could initiate and strengthen how HCPs worked with communities to improve healthcare through these cycles. There were examples of QI methods being adapted and successfully used to foster collaborative working as a process for healthcare improvement.

My findings show that the use of QI methods can advance PHCP co-creation. The examples studied in this thesis show the public and HCPs used these methods with a spirit of improving co-creation as a process for improvement. QI methods were seen to offer a structured approach that could advance the learning and practice of co-creation. This happened successfully in contexts where these methods were already used as means to improve healthcare. However, even in this context public partners were not always aware of the QI methods being used. It was common for the public to be kept away from the methods and not be trained in their use. The use of methods could alienate public co-creators and appeared elitist[114]. In atypical situations, public partners had more knowledge and experience in using QI methods than HCPs and sometimes brought these methods into healthcare settings. My data did not describe examples where QI methods were used with fidelity. Namely, the methods were not always used as intended[143,145] and were not fully documented in the case of PDSA cycles[143,145]. However, these methods still proved beneficial to embed or reflect on a collaborative practice.

While some research attempts to resolve issues of fidelity surrounding the use of methods[141,143], my findings question whether use of QI methods should be 'good enough' (7.5) . The concept of 'good enough' comes from Durose et al.'s (2017) work and offers an alternative consideration to capture evidence for coproduction[381]. I use this concept to ask, if the use of QI methods is seen to advance collaborative practice or reflection of its impact, is that 'good enough'? Some researchers suggest method is needed rather than initiating unplanned healthcare improvements[112], but evidence that QI methods improve patient care is limited[120,124,144–146,382]. Walshe (2009) cautions us to critique and understand the evidence underpinning QI methodologies rather than sweepingly bringing these in for widespread use[120]. My research shows we need to be careful to not perpetuate a neo-colonial approach to QI. In other words, we should be considerate of pre-existing cultural contexts and ways of doing things, rather than enforcing methods without regards to current, prevailing practices[120,286]. 'Good enough' use of QI methods in these findings strengthened relationships between the public and HCPs, and enabled them to advance healthcare improvement (7.2.3;7.4.3).

2. Value co-creation: an explanatory theory for PHCP partnerships

Value co-creation (VCC) has been introduced as an explanatory theory that could strengthen PHCP partnerships. It has been applied in this thesis to understand partnerships between the public and HCPs, and provide suggestions for improvement. The biggest potential of VCC is its aim to build a collaborative relationship between those traditionally positioned as creators and consumers[82,85,86]. As explored throughout this discussion, this collaboration could come from bringing together the public and HCPs with supportive practices and facilitative engagement platforms.

VCC offers a way to make explicit and overcome traditional power dynamics. Specifically, dynamics that place patients as passive receivers of care delivered by HCPs, who could also be positioned as the 'gatekeepers' of service improvement[199,201]. The 'co' in co-creation provides the potential to establish a relationship of equals among the public and HCPs. However, in practice the data often presented power dynamics that influenced how effectively the public and HCPs worked together and shaped healthcare improvement. For example, while public partners had to meet financial costs of co-creation such as printer cartridges, this was not the case for individual HCPs (chapter 6). Public partners in initiatives Woke and Jugat relied on HCPs to invite them into traditionally HCP-owned spaces (chapter 5). This could favour particular members of the public who were seen as being able to behave in 'the accepted manner' to participate, as opposed to others who may provide more challenge. This aligns with wider literature highlighting ways in which organisations limit the potential of the public to fully shape healthcare change[63,170]. It mirrors Stewart's (2016) discovery that organisations structure what is deemed acceptable PI[59]. However, she also emphasises adversarial relationships between services and the public could produce something more generative than may otherwise be realised when relying on apathetic individuals[59].

My findings show some organisations (Ekta, Deep, Tayjan; Chapter 4;5) enabled and optimised these adversarial relationships. They did this by resourcing, initiating, and managing PHCP relationships regardless of how challenging these could be. All three saw PHCP relationships as worth nurturing through financial resources and staffing. There was senior leadership commitment throughout the organisations for this way of working, and these leaders publicly positioned co-creation as integral to healthcare improvement. Crucially, all three organisations initiated dialogue, and continued to be reflexive during problematic or tense situations. This dialogue, together with levels of transparency, enabled the public to take their places as partners in healthcare improvement, and in a collective learning journey. It allowed for generative, adversarial relationships where tension became productive, and advanced healthcare improvements being made, or progressed a collaborative way of learning and working.

The public could also have more power than their HCP colleagues. As Armstrong et al. (2014) found, the public could also be "*technology of persuasion:* a means of influencing opinion and debate"[78(p7)] (see chapter 4). The public could convince organisations to support improvement initiatives or became mechanisms that ensured accountability. Data from initiative Jugat highlighted public partners were a reason specific tasks were completed. This, therefore, warrants alternative analyses of PHCP power dynamics. Clarissa Hayward states:

> "we should define power, not as an instrument some agents use to alter the independent action of others, but rather as a network of boundaries that delimit, for all, the field of what is socially possible."[383(p3)]

Seeing power in this way could establish further understanding of the mechanisms that limit the freedom or constrain the actions of HCPs, as some see them as holding the power. Such analyses could add to the growing debate about how to practically realise coproduction in healthcare. It could uncover learning to increase the likelihood of more successful interactions, such as, those in initiative Samaaj (Chapter 5). Public and HCP partners in this initiative used their strengths to optimise how they worked together to improve peer management of a chronic condition. The public partners were crucial to tailor and drive the initiative for potential beneficiaries because of their experience of the condition. The HCP partners were necessary to manage relationships with complex healthcare and related structures. Transparency and regular reflection on how they worked enabled them to manage tension as it occurred.

The success of VCC as an explanatory theory comes from its positioning as interactional creation[88] and through the interconnected DART model[82,86]. As previously described, VCC helps make explicit the "informal theory [that] is always at work in improvement, [but that] practitioners are often not aware of…or do not make it explicit"[126](5.8.4). The VCC theory provided a framework to understand the complex picture of multifaceted PHCP co-creation that in line with Deleuzian assemblage theory[264,266,267] can be both interrelated with, and distinct from, surrounding health and care systems. Initiatives Samaaj and Connect provided useful examples of this with the HCP collaborators being part of, and even directed by, the health and related systems in which they worked. However, the public partners could be independent entities continuing the initiative's work in ways that they felt added value, even if this was outside of the scope of the initiative or the related organisations. There were examples in both these initiatives of public partners establishing co-creation activities connected to the projects but independent of the surrounding organisations. The interactional nature of co-creation provided a framework that broke down PHCP co-creation into a series of interactions (sub-section 8.3 part 1). The DART model helped to uncover the complexity of personalised experiences and high-quality PHCP interactions. The DART components were tested and refined through the cases and examples of co-creation that were assessed through this research (3). Thus, Ramaswamy and colleagues' value co-creation[82,85,86] provided potential direction and useful explanations of the core components of otherwise diverse and unique ways of working. This level of detail may make it easier to prospectively and proactively manage PHCP co-creation to ensure this way of working "realizes its full potential"[78].

But VCC was limited as a middle-range theory when describing PHCP co-creation and its relationship to the design and use of engagement platforms in the contexts studied. Ramaswamy and Ozcan describe the importance of bringing together artefacts, processes, people, and interfaces (APPI) as platforms for engagement[86,88]. My application of APPI as an explanatory theory found these components do exist in platforms set up to facilitate PHCP co-creation for healthcare improvement, as demonstrated across the six organisational case studies (C5, C7). The theory, therefore, offers useful, micro-level explanation of the types of components that are necessary to create more participatory platforms. But my data demonstrated variation and disengagement by the public and HCPs can still occur even when the APPI components existed, and sometimes because of the APPI components (C5). Regular collaborative learning events, for example, were purposefully designed engagement platforms that combined the various APPI components (5.8). However, these disengaged some public partners in initiative Samaaj, and never quite led to full engagement from public or HCP partners in initiative Jugat. APPI provided a way to understand the design of engagement platforms when they led to successful engagement, but was insufficient in its current form to explain the nuances that limited engagement.

There should be exploration of whether the fundamental premise of engagement platforms and APPI is at odds with PHCP co-creation in service change then or if they require adapting. I previously expanded on how the theoretical underpinnings of VCC[88] (assemblage theory[264,267] and sociomateriality[265]) enabled this approach to be transferable to different contexts and transformative in what it could realise (2.4.3). I have demonstrated the potential of Deleuzian assemblage theory for PHCP co-creation (pgs.244-245;260), but there was less evidence of the potential for sociomateriality from my analysis. Sociomateriality "posits the constitutive entanglement of the social and the material in everyday life"[384] and is crucial to organising. Orlikowski and Scott (2008) acknowledge the interrelated nature of technology, work. and organisation fundamental to sociomateriality bring challenges because of the divergent definitions of technology[265]. Core elements of the diverse definitions could include Information Technology, or combinations of objects, actions, processes, and contexts and so forth[265]. These core elements and related definition of technology may influence whether APPI can be applied to situations where core co-creation activities are not centred on technology, such as some of the improvement initiatives in this study.

Ramaswamy and Ozcan's (2018) more recent articulations of APPI appear to be influenced by an increasing digitalised business world and position the combination of these components as digitalized interactive platforms[348]. The APPI components like Artefacts and Interfaces can be "physical and digitalized"[88] but my exploration has been in cases focusing on four initiatives of which only two had significant digital components (5.6-5.7). As previously described, the digital components in initiative Jugat particularly were contentious and could disengage some while engaging others (pg.232). This analysis provided a useful test of the potential of APPI to explain meaningful PHCP co-creation, including the first translation of the components for PHCP working in healthcare improvement. This crucial step can now be built upon in a prospective application of PHCP co-creation, and broader exploration of the design of facilitative 'engagement platforms'. Such research should explore whether the implementation of APPI could improve the effectiveness and design of engagement platforms when they may be counter-culture, and where engagement is a supplementary rather than primary purpose of improvement. Additionally, it should aim to understand how fundamental the technological aspects are to facilitative engagement platforms.

This thesis has initiated use of value co-creation as a middle-range, explanatory theory to optimise PHCP partnerships. It provides a useful step forward but further research is needed to ascertain whether this leads to participatory working as a "better science"[385] that evolves healthcare improvement.

3. Adding to the debate about impact of co-creation: the Experiential-Tangible Value model

Staniszewska et al. (2011) argue that the impact of PI needs to be measured[238]. They proposed "well-developed instruments can provide a quantitative assessment of a qualitative construct"[238], and emphasise the public must be involved in establishing these instruments. A key consideration they note is for whom impact would be measured and accordingly what it may need to demonstrate[238]. Staley (2015) questions the meaningfulness of such measurement[105]. She highlights such measurement would provide context-specific evidence of impact rather than generalisable predictive offerings, particularly because of the experiential and subjective nature of PI[105]. Staley proposes we need to further understand what works in different contexts to understand the factors that enable PI to achieve successful outcomes[105].

This thesis contributes to this debate by developing my novel Experiential-Tangible Value model (6.2.4, Figure 18) that makes explicit how cultural norms and assumptions influenced what was deemed value (6.2). The model describes types of value realised through the co-creation process, be it experiential, tangible, or both, for instance, that which sits in the intersection between these two spheres. The model described how the relationship between the individual and their place in the co-creation process, influenced what was deemed value and by whom. Thus, the model developed as part of this thesis responds to Staniszewska et al.'s (2011) assertion that the "for whom" surrounding impact is important and describes how the position of the "for whom" influences what is deemed value. Experiential value was the value realised through the co-creation process. This included improved relationships between HCPs and their patients or increased public awareness of how healthcare systems work (7.2.1). Tangible value included healthcare innovations such as the patient-held document that PHCP in project Woke co-created (5.4.3). The Experiential-Tangible Value model illustrated tangible, visible value was more likely to be deemed value by those external from the co-creation process. Experiential value was more likely to be acknowledged by those who were part of the co-creation process. This model therefore corroborates Wenger et al.'s (2002) concept of the 'tangible value' of communities of practice which they say "provides [the communities] with the legitimacy they need to steward knowledge effectively"[386(p15)]. My analysis found a similar relationship between the initiatives which realised tangible value and the legitimacy these garnered as examples of successful co-creation.

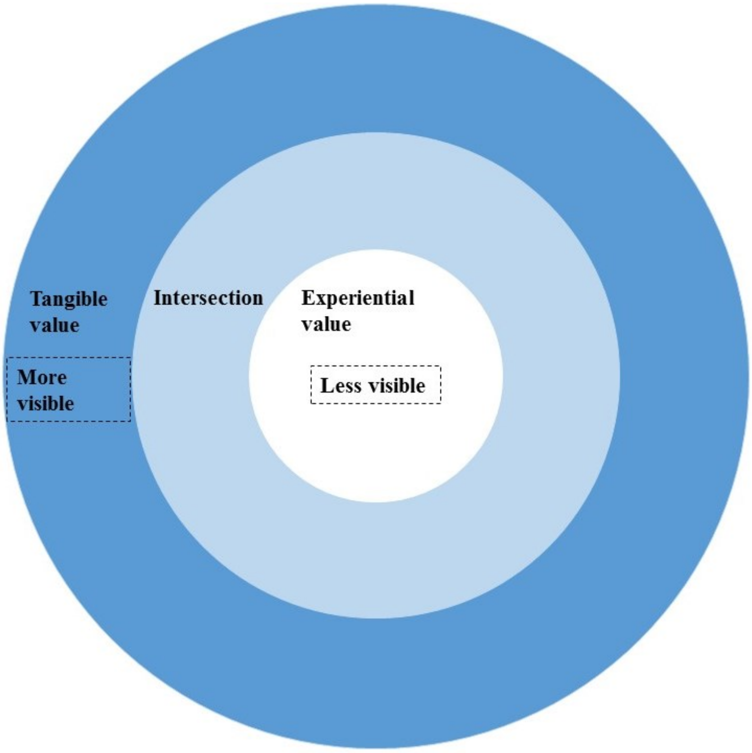
My model further adds to the debate about the impact of PI by positioning experiential value as a potential precursor to tangible value. This is demonstrated by the increased awareness of healthcare systems and the improved relationships among the public and HCPs realised through co-creation that led to these individuals co-creating innovations (4.3.3;4.3.4;5.7.3). Conversely, the healthcare innovations could improve other people's experience of using healthcare. The patient-held document PHCP co-created in initiative Woke provided information that helped prevent treatment that could have threatened a person's pregnancy (5.4.3). Additionally, processes such as CHWs sat between experiential and tangible spectrums because of the value the individuals realised by being part of the initiative, or through demonstrable outcomes (5.5.3;6.2.3). Project Samaaj realised experiential value for CHWs and HCPs who were part of, or leading, the initiative. However, the CHWs and HCPs were able to collect enough quantifiable data through use of rapid and regular measurement to evidence they had co-created a useful mechanism that warranted continued support.

Exploring alternative approaches to measurement, as initiative Samaaj did, that have not yet been applied to PHCP co-creation could provide potential solutions to add to the debate about impact of PI. Solberg et al. (1997) describe three reasons for measurement: improvement, accountability, and research[387]. Each is useful in different ways for different audiences depending on the purpose. They argue "data for accountability, which are data on outcomes or results, do not usually illuminate how the outcomes were achieved or how processes might be changed to improve them."[387] To counter this, they propose measurement for improvement. This focuses on easy to collect, regular, small-scale quantitative data that provides enough evidence for rapid review of processes and practices[387]. Such data is regularly analysed and presented on control charts that show whether processes and practices have led to improvements[388].

Project Samaaj's use of measurement for improvement is explored in Chapters 5 and 7. In summary, the data enabled the team to understand what was working and direct energy towards those parts of the initiative. This measurement approach enabled them to reflect and collect data that was deemed 'valid' by those external to the process. Therefore, this reflection enabled PHCP in Samaaj to realise they should document qualitative information captured through their interactions with the initiative's target population. Measurement for improvement offered a way of providing "a quantitative assessment of a qualitative construct"[238]. It met these purposes so well that they continued to actively collect data in this way for seven years after the project was initiated.

The Experiential-Tangible Value model could provide a way to plan "good enough"[381] impact assessment. As stated before, Durose et al. (2017) propose collecting 'good enough' evidence specifically for coproduction initiatives[381]. They argue such evidence could overcome challenges to evaluating coproduction caused by the divergent definition of the term and the relational aspect of coproduction practice[381]. The Experiential-Tangible Value model (Figure 18) aims to describe that the value of co-creation can be experiential, tangible, or both. The model aims to aid discussion among PHCP co-creators to enable them to define the value they aim to realise, and provides a tool to reflect on their achievements at various points throughout their journey (6.2.4). Crucially, it provides an impetus for PHCP co-creators to have explicit conversations about value throughout their initiatives and be able to articulate what this means to them. The model could help initiatives consider the type of value they aim to realise and how they are evidencing this. The public and HCPs who are part of the initiative could then consider whether the value they are currently evidencing is ‘good enough’, or whether they want to strengthen and supplement this through other approaches.

Figure 18: Experiential-Tangible Value Model



8.6 Summary of Impact

I have outlined the importance of investigating how PHCP working can be optimised for service change (1; 2). Universities are required to consider the impact of the research they conduct and support as part of the criteria in the Research Excellence Framework. The Research Councils UK defines this impact as Academic, Societal and Economic[389]. This research contributes to all these criteria (Figure 25):

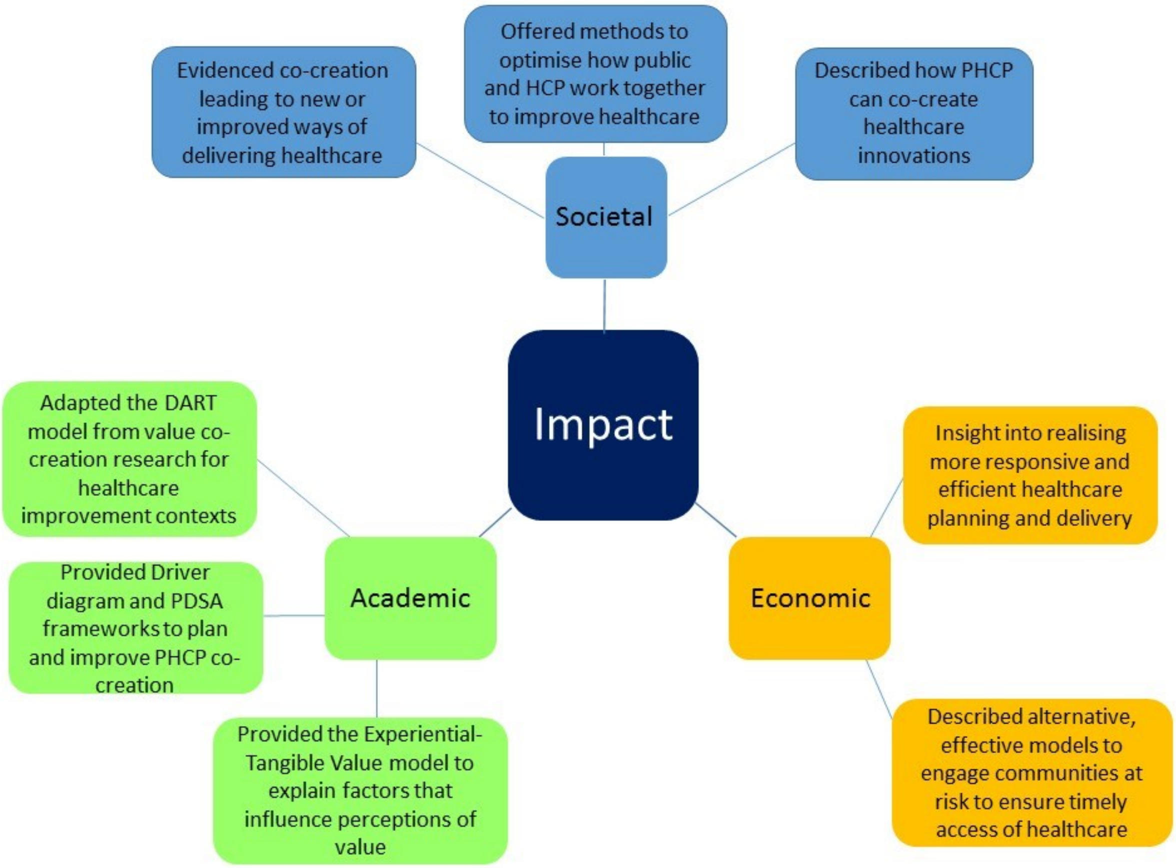
- **Academic:** This research tests and adapts existing theories and findings from the value co-creation literature. This included translating Ramaswamy and colleagues’ DART model[82,86] for healthcare improvement by defining its components. It applies these to PHCP co-creation for healthcare improvement often providing the first such adaptation for this setting. Additionally, it created frameworks from the QI methods used in improvement initiatives that can provide a way to plan and formatively evaluate co-creation. This work makes a novel contribution with the Experiential-Tangible Value model that could add to ongoing dialogue about perceptions of impact.

- **Economic:** This research demonstrates how PHCP co-creation realised more responsive, efficient healthcare planning and delivery. Connected to this, it described how the public and HCPs worked together, and worked with target communities including those who should be accessing specific healthcare services or receiving help to more effectively manage their conditions. The combination of these two areas led to people accessing more responsive, timely, effective healthcare, rather than delaying or not receiving treatment or support. This could, therefore, alleviate the economic costs of delayed or inappropriate care.

- **Societal:** This research provided explanations and generalisable methods to optimise how the public and HCPs worked together. This could therefore increase the likelihood that PHCP co-creation realises societal value through new and improved ways of delivering healthcare. This work described how the public and HCPs worked together to co-create healthcare innovations that provided value for people who were not part of the original improvement initiatives.

Continued overleaf.

Figure 25 Summary of Impact



8.7 Reflections of study design and limitations

This research was framed by a participatory paradigm and conducted using a mix of collaborative inquiry and an ethnographic approach. This section considers this study design and discusses the related implications and limitations. Six areas are discussed: the participatory paradigm; the influence of reflexivity on the research process; the ethnographic approach; capturing privileged experiences; learning from success; and describing engagement platforms for PHCP co-creation.

8.7.1 The participatory paradigm

This study aimed to be participatory in an attempt to bridge the gap between research and practice[302,390]. This meant the research process aimed to be carried out *with* people rather than on, or for them[298]. This paradigm includes many different research approaches and I aimed to adapt these to take into account the public and HCPs' other priorities and the time they had. I, therefore, aimed to embed participatory approaches in organisation Deep, and at least one improvement initiative over the course of the data collection phase for this research. The participatory research was to be conducted in various ways. More formal, structured action research[302] was originally planned for organisation Deep. This aimed to be conducted through adapted co-operative inquiry[295,298] that aimed to offer more flexible space for collaborative investigation and reflection to inform and shape the ongoing research process and the findings that emerged.

While this research managed to gather useful findings to bridge the gap between research and practice, the research approach did not fully model PHCP working. The biggest restriction to modelling PHCP working was the limited, formal, reflective collaboration, and therefore this research was not as participatory as planned. There were challenges to embedding participatory approaches largely relating to competition with existing priorities (pg.68). Attempts were made to create spaces for Action Research sets in organisation Deep and with initiative Jugat but these were unsuccessful. Less structured collaborative inquiry was, therefore, implemented in organisation Deep and ethnographic observations from initiative Jugat were fed back to adapt interventions that aimed to improve PHCP working. These extra efforts were needed to ensure the public and HCPs who were part of the organisation and the initiative had opportunities to share reflections during the research process.

8.7.2 The influence of reflexivity on the research process

The research process and results were influenced by reflexivity throughout this PhD. May and Perry (2014) state "reflexivity is not a method, but a way of thinking or critical ethos, the role of which is to aid interpretation…, translation and representation"[391(p111)] for knowledge production. Sub-section 8.7.1 incorporated the collective reflexivity that took place through adapted co-operative inquiry. This sub-section, therefore, focuses on the influence of reflexivity on my position as a researcher, my process, and how my research evolved as a consequence.

Reflexivity focused, strengthened, and evolved the theorisation that emerged through this study. Kislov et al. (2019) describe theorising "as a set of processes that aim to use empirical data actively in developing, validating, modifying, and advancing conceptual knowledge in the field". Collins (2009) goes further to emphasise the micro-level reflexive processes and describes how her own theorising advanced through interactions in everyday activities. She stated her informal interactions with Black women, that were outside of her core research activities, provided fora that strengthened her articulation of Black feminist thought.

I described briefly how my personal and professional experiences provided me with the necessary interactions through which I enacted my own thought-action process that advanced my theorising (3.1). My interactions as a patient, carer or friend enabled me to experience collaborative approaches (or the lack thereof) in health and care delivery. My professional interactions with others working in healthcare improvement or PI highlighted continuing challenges, but also the potential of QI or collaborative approaches for healthcare systems change. My interactions and experiences in these two spheres (patient/carer and professional) iteratively shaped and strengthened my solution-focused approach in this study. For example, my interactions in the two sphere led me to realise that HCP roles in PHCP co-creation were equally important to the success of this way of working, yet underexplored. This realisation created the impetus to test, refine, and expand Nambisan and Nambisan's (2013) roles of citizens in co-creation[279] to articulate necessary positions all co-creators could play. My own reflexivity and understanding about the ongoing debate about how to measure the impact of PI[102,237] led me to test and refine the resulting frameworks (sub-sections 7.3.1 and 7.3.2). The Driver Diagram and Plan-Do-Study-Act cycle frameworks created were true to the data I collected, but aimed to be equally useful for people with different or no QI experience. My own thought-action process, therefore, helped me to test multiple directions for this research and hone in on practicable solutions to improve PHCP working.

My own reflexivity was, therefore, critical as a way of connecting theory and practice and highlighting the potential relationship between PHCP working and the theory of value co-creation. This interplay strengthened my own intuition derived from my experience as a co-creation practitioner and my ongoing reflexivity. Describing the philosopher José Ortega y Gasset's work on experience, Fals-Borda (1991) states "through the actual experience of something, we intuitively apprehend its essence; we feel, enjoy and understand it as reality, and we thereby place our own being in a wider, more fulfilling context"[392(p4)]. Fals-Borda states both experience and commitment are keys aspects to produce knowledge that challenges and transforms existing hierarchies between researchers and the researched[392]. Specifically, conventional learning and implicit knowledge form experiences that can bridge theory and action and produce "people's knowledge"[393]. This knowledge becomes "dialogical research, oriented to the social situations in which people live, attempting to organize them and to break up the subject/object binomial"[393(p149)]. This process of knowledge production challenges what is deemed valid, positivist or 'scientific' knowledge[287,291,392,393].

My process of knowledge production strengthened by my personal and professional interactions in various contexts enabled me to reflect on, and experience, the potential of Ramaswamy and colleagues' DART model[82,85,86]. My own reflexivity and dialogical research with the public partners and HCPs who were part of my research and personal interactions, enabled me to draw connections between PHCP co-creation, and Ramaswamy and colleagues' value co-creation theory[82,85,86,88]. This helped test, refine, and define the DART model (sub-sections 4.2 and 7.1.2), and ultimately provide something potentially useful to those working in healthcare improvement contexts. This approach, and the centrality of my own reflexivity, therefore, helped bridge the gap between research on co-creation, and its relevance to practical service change.

8.7.3 Ethnographic approach

This research aimed to apply an adapted ethnographic approach where specific, anonymised observations would be fed back to support initiatives and organisation Deep improve how PHCP co-creation occurred. This was in line with Iedema's work of feeding back data to HCPs to support improvements in practice by strengthening capacity for reflexivity[327]. This worked well for organisation Deep where HCPs felt the observations provided them with insights to inform interventions to improve PHCP co-creation. Specific observations about the improvements being made were also useful for one of the initiatives. However, it was more challenging to feed back this data to improvement initiatives when the data critiqued their practice.

The relationships that I developed with individuals and the initiatives and organisations impacted how easy it was for me to feed back data that critiqued practice. For example, initiative Jugat did not meet regularly which impacted the relationship I formed with them and reduced my ability to regularly feed back findings. As such, I used more traditional ethnographic observations with them, and there remained a distance between myself as a researcher and the researched initiative. This distance challenged the participatory paradigm that framed this research and questioned whether this research could be participatory at all levels. This did not impact the usefulness of the data collected but influenced the extent to which this data could be used for improvement. The relationships formed, therefore, limited the type of data I could feed back to the improvement initiatives and may not have optimised its influence on practice.

The amount of data collated through the ethnographic work was extensive and the level of work involved to observe practice made it impossible to fully observe everything. The ethnographic approach therefore focused on situations where PHCP co-creation took place and ignored day-to-day improvement initiative activities. The influence of daily healthcare practice on PHCP co-creation was not fully explored and would be an interesting area for further research.

8.7.4 Capturing privileged experience

There have been long-standing calls to bring diversity into PHCP co-creation[23,156,235] and the wider literature reminds us of the impact of people's various identities and experiences on their lives. Kimberle Crenshaw's exploration of black women's experiences of race and gender discrimination and violence, highlighted the multiple levels of oppression they face because of being black and being women[394,395]. Crenshaw describes how the severity of their experiences can be perpetuated through their various identities, and yet these multiple levels of oppression are not always recognised or acknowledged especially in societal structures[394,395]. In these societal structures, for example, the legal systems, a single-axis framework exists that sees race and gender as separate parts of people's experience[394]. Crenshaw (1989) states this single-axis erases the experiences of black women and promotes the experiences of otherwise privileged women[394].

This thesis captures and describes experiences of specific groups of 'privileged' public and HCPs. The participants of this research represent a similar demographics. They were all competent, articulate, and reflective. The HCPs held middle to senior-level posts, while most public participants had degrees or significant work experiences. The data did not include demographically diverse people although there was some diversity by ethnicity and age. The participants in this research were ultimately people who had the agency to engage with my study. They saw the research call or agreed to my request to observe their practice and were, therefore, in some way connected to the spheres in which I publicised my research. These public and HCPs were not lone, unconnected people who may struggle or refuse to be involved in healthcare improvement. They were experienced people with the potential and ability to influence service change, even if they felt what they achieved was ultimately limited. This research did not include individual HCPs who were unable to take up healthcare improvement or not afforded the opportunity to do so. Therefore, this study by its nature captures the experiences of the privileged and excludes various public and HCPs whose insights could further expand the understanding of co-creation (or lack thereof) for healthcare improvement.

8.7.5 Learning from success

The research structures that surrounded this work can perpetuate concepts such as having ‘enough’ data (3.6.1). This led to me seeking positive examples where I could ensure a minimum level of PHCP activity (C3), and has advantages and disadvantages for the conclusions drawn.

Researching positive examples with a minimum level of PHCP activity has been useful and presented interesting findings to address the research questions. Specifically, the data has enabled me to provide potential solutions to help optimise PHCP co-creation for healthcare improvement. These solutions were strengthened by the comparable data from multiple, successful cases in this thesis. The data came from a range of similar contexts, or from organisations that adopted comparable approaches to healthcare improvement (C3). These similar cases added to existing research on co-creation in healthcare improvement by investigating multiple sites and various programmes, and provided some generalisable findings.

However, learning from success as an approach offers a limited view of the reality of PHCP co-creation for healthcare improvement. In particular, it focuses on those who carry out PHCP co-creation rather than attempting to provide answers that could shift practices of those who do not adhere to this way of working. Specifically, the voices of those who are sceptical of PHCP co-creation are missing, as are observations and descriptions of cases where PHCP working was absent. Such examples would have provided useful data on the challenges to PHCP co-creation practice in healthcare, and provide insight and solutions to tackle these challenges.

8.7.6 Describing engagement platforms for PHCP co-creation

This thesis introduced one particular theory which described the components necessary in platforms that can optimise engagement. The data demonstrated that such platforms are constructed in a considered and purposeful manner to facilitate PHCP co-creation in some of the healthcare improvement initiatives studied (5.8.4). There is then, a science to facilitating

PHCP co-creation that PI practitioners, in particular, appear to enact. However, the explorations about the specific nature and design of platforms that facilitate interactions between the public and HCPs were from one healthcare improvement programme (Deep; 5.2.1;5.8.2), and were described using one theory that has never previously been applied to PHCP co-creation.

This research was not able to conclude that Artefacts, Processes, People and Interfaces were the only core components necessary to optimise platforms to facilitate high-quality interactions between the public and HCPs that realised value. It was also unclear whether all the APPI components were equally necessary and positively influenced co-creation in healthcare improvement initaitives. The APPI components, therefore, provided a useful initial exploration of such platforms, but appeared to be the weakest aspect of the VCC theory when applied to PHCP co-creation in service change. While APPI was useful in describing successful interactions between the public and HCPs, it did not enable understanding of more challenging interactions that occurred because of these four components (5.8.2). This may be because APPI was used to help make explicit these platforms rather than purposefully design them in line with Ramaswamy and Ozcan's concept[88]. It could also relate to the fact that this theory was not always used in initiatives where there were core technological or digital elements.

It would, therefore, be useful to research a broader concept of engagement platforms for PHCP co-creation in different settings, and make explicit core components that are informed by various theories. This could provide a richer understanding of 'what works', including the relationship between the successful design of such platforms, and the relationship between these and the dominant practices in the contexts in which they are being implemented.

8.8 Areas for further research

Areas for further research were highlighted throughout this thesis and some of these are expanded on below.

Challenging the DART model

Dialogue, Access, Reflexivity and Transparency have been shown to have some usefulness and validity in this setting. This thesis presents a novel adoption and adaptation of the DART model[82,86] (C4, C7) in the healthcare improvement context, and it may be deemed to present a particularly positive view of the model. My research tended to corroborate Prahalad and

Ramaswamy's assertion that DART are the "building blocks" for interactions[82]. I did not find cases that challenged the relationship of the DART components to PHCP interactions. It would be useful to research DART further to test its limits and to understand whether specific DART components are more important than others. Additionally, such research would benefit from exploring the potential and use of the DART model to manage tension among public and HCP co-creators.

Use of QI methods to improve co-creation

My research found QI methods were used to plan and improve PHCP co-creation for healthcare improvement (C7). Based on this data, frameworks were created for driver diagrams and plan-do-study-act cycles that could be used to formatively plan and evaluate PHCP co-creation (C7). Further research should test the usefulness of these frameworks in various contexts, including for PHCP co-creation in more traditional research settings. Additionally, it would be useful for this research to explore whether these frameworks could offer 'good enough' approaches to plan and formatively evaluate co-creation.

Experiential-Tangible Value model

The Experiential-Tangible Value model created from the data collated during this research described variations of perceptions about the value of PHCP co-creation (C6.2). The data showed why something is deemed value is influenced by who is assessing this and how the value manifests (C6.2). There is a difference in what co-creators see as the value realised through co-creation (experiential) and what others external to this process see as value (tangible) (C6).

Further research should explore the usefulness of this model in helping public and HCP co-creators discuss the value they feel they are realising and evidencing. The research should investigate whether the model offers a 'good enough' approach that helps make explicit the value of co-creation, and whether this leads to co-creators taking any different action. Could this model help public and HCPs manage the realisation of value in initiatives aiming to improve healthcare. This could encompass investigation into whether the model aids discussion about value among PHCP co-creators, and whether this helps initiatives formatively assess and manage the value they realise.

Decolonising QI and Co-creation

Among continuing challenges to engage demographically diverse populations to improve healthcare[23], and concerns around the potential of specific QI methodologies being pseudoinnovations[120], exploring the need and potential of decolonisation could offer a radical challenge to the status quo. "Decolonization involves profound transformations of self, community, and governance structures"[315(p3)]. It aims to remove colonial influences on structures, practices but also perceptions of knowledge. Such influences have led to hierarchies of more valid knowledge and current structures and practices being founded on perceptions that the West is the best[286].

My research described structural influences on both QI and co-creation and demonstrated challenges to perceptions that QI and co-creation must happen in specific ways (C4, C7). Diverse approaches taking into account current practices in traditional healthcare or community settings appeared to achieve value for healthcare improvement (C4, C7). This was especially the case in the community setting in the UK and in Sub-Saharan Africa where flexible and varied PHCP co-creation and QI was evidenced (C4, C5, C7). Successful engagement with communities in Sub-Saharan Africa depended on an acceptance by the QI programme Jinja that the community could conceptualise their own problems and implement their own solutions (C7). This led to them exploring new ways of delivering QI in such communities keeping in mind the abilities, knowledges and potential that existed in these settings (C7).

This, therefore, offers potential to explore decolonisation for both QI and co-creation. Research should explore what decolonisation of QI and co-creation would mean, and how it would account for divergent practices in communities and traditional healthcare settings. Such research could investigate varying cultural practices even within traditional healthcare settings, and cultural acceptance of co-creation and co-created innovations. In terms of QI, such research could explore the extent to which a neo-colonial approach to QI is practiced in healthcare. Specifically, whether there are adapted ways of using QI methods, or if alternative practices in specific settings can be useful.

Community Health Workers models: a potential approach for the NHS?

This research demonstrated variations of CHW models that were used in Sub-Saharan Africa and across the UK (6.2.3;5.5). These models enabled members of communities to become intermediaries between traditional healthcare settings and specific populations. The CHWs would provide basic advice to help people better manage health conditions, or triage them into existing healthcare services. My data evidenced these models were able to form a productive way for the public and HCPs to work together and provided effective, supplementary healthcare systems. And it also demonstrated various adaptations of these models and the strength of CHWs appeared to come from their flexible, community-facing nature. Existing research has demonstrated the potential of the CHW model to support improved effectiveness and efficiency in the NHS[396].

However, further evidence would be useful specifically to understand optimal designs of the CHW model, and how the models are adopted and adapted in practice. It would be useful to explore ownership and power hierarchies to understand whether these models are perpetuating existing structural dynamics[397] in traditional healthcare settings, or whether and how they enable responsive, supplementary healthcare systems. Additionally, it would be useful to explore the extent to which this model would be able to support responsive healthcare. In particular, could it provide a solution to what individuals in communities need rather than what healthcare institutions think they should deliver? Could CHW models support a shift away from institutionally-focused and towards more community and people-focused healthcare?

8.9 Implications and Recommendations

My research has identified potential implications, and recommendations for both policy and practice which are summarised below:

Enable and Support Public Leaders for Improvement

This research demonstrated that public co-creators who are trained and supported to lead healthcare improvement can deliver service change. However, the public were not always provided with such training and the support to carry out this work. Furthermore, the public co-creators were dependent on existing QI organisations providing them with such training and enabling them to initiate improvements.

There is a need for more independent structures that can bring together public and HCPs who want to improve healthcare. Such structures could provide autonomy and resources, through funds, to public-led healthcare improvement and enable equality of access to public leaders with ideas to shape improvements.

Facilitate ‘good enough’ research for improved research and practice

There is an acknowledged gap between research and practice in healthcare. This thesis builds on Durose et al.’s (2015) introduction of ‘good enough’ evidence for coproduction[381] as a solution that can bridge this gap.

Sharing ‘good enough’ and emerging research findings could offer a way for such findings to be tested to improve practice and working in healthcare. These early tests could continue to contribute to adapt, improve, and establish responsive research. This would need wider commitment, support, and resources, and a shift in expectations towards acceptance of ‘good enough’ research informed practice.

Resource supportive and independent structures and processes for co-creation

All the public participants in this research were dependent on existing organisations to be invited in to influence healthcare improvement. This highlights a fundamental factor impeding equality of access of a demographically diverse group of public co-creators, including those who may not access or be connected with these organisations. This lack of access can perpetuate inequalities between those who have agency to participate in healthcare improvement and those who do not.

Supportive, independent structures for co-creation should sit outside of formal institutions and perhaps within community settings. By being located within communities, these structures could change the dynamics from improvements that are responsive to what institutions think or want, to that which communities and the public need.

Resourcing participatory working and improvement in traditional healthcare settings

My findings found that the time and space required for participatory working for healthcare improvement in the NHS in particular was not protected, despite the fact that such approaches could realise responsive, efficient healthcare planning, delivery, and innovation (C6).

There needs to be commitment to backfill, resource, and support PHCP participatory working in healthcare settings. This should include ensuring bringing together necessary but often overlooked people from diverse demographic and professional backgrounds.

Adapt and apply relevant theories and practices for co-creation and healthcare improvement from other contexts

This thesis demonstrated a need to cast the net wide and find existing theories and practices in different disciplines and contexts that can advance PHCP co-creation and healthcare improvement. We should use the resources that would be used to create new models, frameworks, theories etcetera, to adapt what already exists, rather than always developing new approaches. This includes testing and adapting the use of QI methods to improve co-creation, and learning from existing and localised improvement practices in lower-income countries.

8.10 Conclusion

This thesis has introduced the potentially synergistic relationship between public involvement and quality improvement that could make involvement more effective, and shape more responsive, efficient healthcare improvement. Other literature discussed highlights the impact of PI on QI initiatives (2.2.2). However, this thesis describes how a range of QI methods could improve PI. In doing so, it shines the light on a host of potential ways of improving the PI process and formatively evaluating its impact, reiterating that methods to both guide the process and enable evaluation already exist[190] in different fields. Rather than recreating approaches and frameworks then, this research shows we can adapt learning and existing practise. QI methods, in particular, provide a beneficial approach as they support collaborative reflection and action.

Terms such as Public Involvement do not accurately represent the interactional process between the public and HCPs to improve healthcare. Some may argue this is a matter of semantics. However, this reinforces traditional power structures that continue to place the public as individuals who should be invited to be involved. While co-creation may not be acceptable to some, it does have a potential of articulating more equal relationships which will hopefully emerge as PHCP working becomes more common place. My novel exploration of Ramaswamy and colleagues' contribution to value co-creation has shown this field describes the interactional process[88] behind this way of working[82,85,86]. It shows the components of DART[82,86] are key to quality interactions that increase the likelihood that they realise 'value'. DART goes some way to explain the micro-level of PHCP interactions, and perhaps clarifies a level of detail that can elude social and systems complexity. DART could enable PHCP to manage their interactions with each other and the wider system, and navigate co-creation through complex systems.

This can only happen through ongoing supportive structures that bring together co-creation and healthcare improvement. These structures should focus on supporting individual co-creators who are not necessarily part of organisations. Only then would we be able to optimise the value of co-creation by positioning the public and HCPs as equally powerful and effective healthcare improvers.

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10. Appendices

Appendix A: List of Interviewees

Name of Individual (Pseudonyms)	Organisation	Public or HCP?	Interview duration	Research Phase
Bethan	Deep	HCP	01:21	1
Faith	Deep	HCP	00:50	1
Igor	Deep	HCP	01:03	1
Nii Kpani	Deep	HCP	00:48	1
Noreen	Deep	HCP	00:48	1
Tarrie	Deep	HCP	00:59	1
Mary	Connect	HCP	00:39	1
Nima	Connect	HCP	00:35	1
Pete	Connect	Public	01:28	1
Rita	Connect	HCP	00:50	1
Sarah	Connect	HCP	00:37	1
Chanan	Jugat	HCP	00:51	1
Dorothy	Jugat	HCP	00:42	1
Inderjeet	Jugat	Public	01:20	1
Mandeep	Jugat	HCP	00:48	1
Neena	Jugat	Public	00:48	1
Aisling	Ekta	HCP	01:05	2
Astrid	Ekta	HCP	01:09	2
Ezra	Ekta	Public	01:29	2
Niamh	Ekta	Public	01:05	2
Paula	Ekta	HCP	00:59	2
Arundhati	Jinja	HCP	00:59	2
Jodh	Jinja	HCP	01:05	2
Serj	Jinja	HCP	00:43	2
Aled	Monitor	Public	01:29	2
Mia	Monitor	HCP	01:24	2
Amrit	Stanter	Public	00:46	2
Charlotte	Stanter	Public	00:56	2
Dave	Stanter	HCP	00:49	2
Salima	Stanter	Public	01:13	2
Taylor	Stanter	Public	01:12	2
Grace	Tayjan	HCP	00:45	2
Ajeet	None	HCP	01:02	2
Chris	None	Public	01:21	2
Dolores	None	HCP	00:58	2
Isabella	None	Public	00:59	2
Krisztina	None	HCP	00:36	2
Nana	None	HCP	00:49	2
Rohinton	None	Public	00:51	2

Appendix B: Observations log

Organisation Deep

Date	Description: Initiative Deep (Collaborative Inquiry)	Time	Observational Minutes
01/07/2015	Widening and Strengthening Involvement in Quality Improvement	11-13:00	120
04/08/2015	Use of 4PI Plan	9:30-11:30	120
01/09/2015	Use of 4PI Study	15:00-16:00	60
06/11/2015	Use of 4PI Study and Act	13:00-15:00	120
16/12/2015	4PI PDSA with QI facilitators		
19/01/2016	Prepare 4PI for Jugat	14:30-16:00	90
25/02/2016	Session with QI facilitator for Jugat	08:30 - 10:30	120
09/03/2016	Delivery support session	09:00-10:00	60
19/04/2016	QI facilitator action learning session	13:00-14:00	60
18/05/2016	Delivery support session	09:00 - 10:30	90
12/07/2016	Action learning discussion	14:00-15:00	60
06/09/2016	QI facilitators action learning	13:00- 14:00	60
		Total hours	16

Initiative Jugat

Date	Description	Time	Observational Minutes
20/11/2015	Driver Diagram	14:00 - 17:20	200
20/01/2015	Measurement and PPI meeting with Pablo and Zora	11:05-13:40	155
12/02/2016	Nominal Group Technique	13:00 - 16:50	230
24/03/2016	PHCP interface	12:20 - 16:45	265
09/05/2016	Clinical team meeting	12:00 - 13:10	70
11/05/2016	Hospital site meeting with Mandeep	12:25 - 13:50	85
26/05/2016	6 month monitoring meeting with Deep	11:00 - 13:00	120
08/09/2016	Jugat process mapping for App	12:45 - 17:00	255

20/10/2016	PHCP interface	10:20 - 16:20	360
12/12/2016	12 month monitoring meeting with Deep	9:00 - 10:35	95
		Total hours	30.6

Initiative Connect

Date	**Description: Initiative Connect**	**Time**	**Observational Minutes**
29/10/2015	Driver diagram session	9:00 - 11:30	150
29/10/2015	Project team meeting	11:40 - 12:15	35
27/11/2015	Project team meeting with JH	13:15 - 14:10	25
04/12/2015	Project team meeting	13:15 - 14:15	60
11/12/2015	Project team meeting	13:30 - 14:30	60
18/12/2015	Project team meeting	13:15 - 14:30	75
08/01/2016	Project team meeting	13:25 - 14:35	70
15/01/2016	Project team meeting	13:30 - 14:30	60
21/01/2016	Process mapping workshop	9:30 - 12:10	160
21/01/2016	Project team meeting with JH	12:15 - 12:45	30
21/01/2016	Taxi ride with Pete and Mary	13:00 - 13:30	30
21/01/2016	Regional [heart condition] Workshop	14:00 - 17:00	180
04/02/2016	Collaborative learning session		Already counted
26/02/2016	Project team meeting	13:20 - 14:30	70
04/03/2016	Project team meeting	13:25 - 14:30	65
07/03/2016	Rita's GP Practice process mapping	13:20 - 14:30	70
15/03/2016	Meeting with GPs at hospital	13:00 - 13:50	50
17/03/2016	Deep initiated Steering Group meeting	15:00 - 16:20	80
21/03/2016	Project Manager interviews	13:30 - 16:30	180
22/03/2016	Process mapping at Little Park	13:00 - 14:15	75
08/04/2016	Project team meeting	13:20 - 14:30	70
11/04/2016	Project team meeting	14:20 - 15:45	85
15/04/2016	Project team meeting	1:20 - 14:30	70
18/04/2016	Maswell Park Surgery process map	12:50 - 14:00	70
22/04/2016	Project team meeting	13:25 - 14:40	75
06/05/2016	Project team meeting	13:25 - 14:40	75
13/05/2016	6 month monitoring meeting with Deep	12:30 - 14:30	120
20/05/2016	Project team meeting	13:20 - 14:25	65
27/05/2016	Project team meeting	13:25 - 14:05	40
10/06/2016	Project team meeting	13:20 - 14:25	65

17/06/2016	Project team meeting	13:30 - 14:30	60
22/06/2016	GP launch ([name] stadium)	10:30 - 18:00	450
24/06/2016	Project team meeting	13:20 - 14:30	70
01/07/2016	Project team meeting	13:20 - 14:30	70
15/07/2016	Project team meeting	13:05 - 14:30	85
11/08/2016	Meeting new PM	10:00 - 11:00	60
12/08/2016	Project team meeting	13:30 - 14:30	60
19/08/2016	Project team meeting	13:20 - 14:35	75
26/08/2016	Project team meeting	13:30 - 14:30	60
02/09/2016	Project team meeting	13:30 - 14:30	60
09/09/2016	Project team meeting	13:20 - 14:45	85
07/10/2016	Project team meeting	13:15 - 14:30	75
14/10/2016	Sarah and Meerat go through questionnaire	13:00 - 13:30	30
14/10/2016	Project team meeting	13:30 - 14:15	45
04/11/2016	PM and Meerat discussing questionnaire responses	11:00 - 11:30	30
04/11/2016	12 month monitoring meeting with Deep	12:30 - 14:10	100
18/11/2016	Project team meeting	13:15 - 14:30	75
21/11/2016	T Shopping Centre session	10:30 - 13:00	150
02/12/2016	Project team meeting	13:20 - 14:30	70
09/12/2016	Project team meeting	13:15 - 14:15	60
23/12/2016	Project team meeting	13:15 - 14:30	*75*
24/03/2017	Team meeting (post baby visit)	13:30 - 14:30	60
22/03/2018	Results feedback at team meeting	13:15 - 14:30	75
		Total hours	71

Appendix C: Interview guide for initiatives in organisation Deep

Investigating healthcare professional-patient/public collaboration in quality improvement initiatives

Main researcher: Meerat Kaur (e mail: m.kaur@imperial.ac.uk ; Office telephone: 020 331 53047)
As part of the CLAHRC NWL programme, we want to investigate more about patient and public involvement in quality improvement.

Aim:
In particular, we're interested in two areas:

1. How healthcare professionals and patients/public work together to improve the quality of healthcare systems
2. How quality improvement teams, plan and manage patient and public involvement in their improvement initiatives.

For this purpose, we will be carrying out interviews with healthcare professionals and patients/public who have worked together in CLAHRC NWL quality improvement initiatives. We are likely to interview you up to three times for the duration of your project.
Go through consent process
Record Date and location of interview
Please note: further probing under these questions is likely to ensure the researcher fully understands the views/thoughts of the interviewee.

1. Can you please tell me about yourself (self, social networks, professional networks as applicable)

2. Tell me briefly about your past experience of being involved in or leading QI initiatives.

3. Can you expand more on the aim of this [QI project]? [enter name of QI project that MK is observing]

4. How did this project come about?

5. How do you see your role in this project?

6. Tell me more about the project team (its structure, its role etc.)?

7. How are decisions made in the initiative?

8. Who brings the resources to the project?

9. Tell me more about how patients/public have been involved in the improvement initiative?

10. What are your views at present on the patient/public involvement in the improvement initiative?

11. Can you think of examples of healthcare professionals and patients/public working together as part of this initiative?

12. What do you think encourages/discourages people to be involved in this initiative?

13. Tell me more about your experience of using QI methods in this initiative.

14. What have you been happy with and what has been a challenge?

15. What does success look like for you?

16. And finally… What do you think you would have been doing if you weren't involved in these projects?

Appendix D: Interview guide for Phase 2 interviews

Consent process, including to record **Date and location of interview**
About you
Tell me about yourself (self, social networks, professional networks as applicable)
Why were you interested in sharing your experiences - what attracted you to the call to share your experiences?
About your experience of QI projects/programmes
Had you been involved in projects or initiatives which aimed to improve healthcare before?
What is your first recollection of hearing about this particular project/programme?
Why did you get involved in these/this project(s)/programme? And/Or What was your motivation?
What is your first recollection of the team? Did you know them before? How did you feel?
About your role in QI projects/programmes
What is your relationship with the project/programme?
What would you say you did in the project/programme?
What do you think your "formal role" was in the project - did it differ from what you actually did?
Your views about how public and healthcare professionals worked
What experience have you previously had of healthcare professionals and the public working together?
How would you describe how healthcare professionals and the public worked in this project/programme?
Tell me about some examples that stick in your head/you recollect about how HCP and the public worked together

Can you think of any quality improvement methods/tools that you were exposed to or used? How did you learn about these and how did you find them in practice?
Your view about what was achieved in those projects/programmes
Going back to the project/programme, what was its aim?
And what do you think it achieved?
Why do you think this is?
And finally…
What do you think you would have been doing if you weren't involved in these projects?
On completion, ask subject to go through the About You form to document their demographics.

Appendix E: Example observation planning using Spradley's observation guide

Project:	**Connect**
Questions:	How do healthcare professionals and patients/public collaborate in quality improvement initiatives?
	What can we observe about how value is created? Actors & Activities
Space	Hospital, GP surgeries, later in the community (define what this means!)
Actors	Healthcare professionals, including Cardiac consultant, GP/commissioner, Patient, Clinical Nurse Specialist, GPs, Project Manager, Ir/regular [Deep] support people - NOT Active patients
Activities	Team meetings; [Deep] events; project meetings on GP sites; workshops presenting the project; events about [chronic condition]
Objects	Phone, ECG device, Use of QI tools, objects that help them interact
Acts	How the team interact with each other, What roles they take on
Events	Team meetings, GP training sessions, community setting, collaborative learning events
Time	18 Months (October 2015 - April 2017)??
Goals	Implementing the quality improvement initiative;
Feelings	Insider/outsider feelings by the team? Frustration of each other/QI/[Deep]

Appendix F: Research call sent to improvement initiatives that may be observed

Investigating healthcare professional-patient/public collaboration in quality improvement initiatives

Main researcher: Meerat Kaur (e mail: m.kaur@imperial.ac.uk ; Office telephone: 020 331 53047)
As part of the [Deep] programme, we want to investigate more about patient and public involvement in quality improvement.

Aim:
In particular, we're interested in two areas:

3. How healthcare professionals and patients/public work together in quality improvement
4. How quality improvement teams, plan and manage patient and public involvement in their improvement initiatives.

For this purpose, we will be observing particular improvement initiatives, carrying out interviews with team members, and observing the team's use of approaches to help plan PPI (such as 4PI).

In practice, this means:

Observing:

- Team meetings (please send dates/locations to the ISM and the person observing will notify the team as to which meetings they would be observing before attending);
- Teams at collaborative learning events;
- Meetings, events or activities related to the improvement being made (which are not covered in the team meetings), e.g. the first test of a checklist to improve the care process on a particular site.

Carrying out:

- Semi-structured interviews with selected team members a maximum of 3 times in the projects life;
- Observations and/or facilitated sessions of the use of frameworks such as 4PI to plan, reassess or test PPI in the improvement initiative.

Collecting:

- Reflections from individuals from the project team (which can be in the form of a reflective diary, or using any other form of media team members prefer, such as blogs, e mails sent to MK, text messages, short video diaries, leaving a message on an answer phone etc.)
- And analysing the team's use of QI methods (such as Action Effect Diagrams, or PDSAs)

Use of the data

Data collected from the observations, interviews etc. will be **anonymised** so comments will not be attributable to individuals. It will be used as part of the Patient and Public Engagement and Involvement theme PhD, which will be awarded by Imperial College London. It will also be used in publications.
We'd also be happy to support teams to write their own papers in the area of patient and public involvement in improvement initiatives, as this area is currently underdeveloped, and would benefit from further research from your projects.

Appendix G: Call to prospective and potential participants for Phase 2 interviews

Learning about healthcare professional-patient/public/community collaboration in quality improvement

We'd like to learn from the experiences of healthcare professionals and patients, members of the public, or communities who have worked together to improve the quality of healthcare services, either for particular groups of patients (e.g. pregnant mothers), or in specific settings (for example, in doctor's surgeries, community health settings or hospitals etc.).

What is the purpose of this study?
We want to learn more about how healthcare professionals and patients, carers or the public, or communities (henceforth patients/public), work together in across a range of quality improvement projects/programmes/initiatives.

We'd like to hear from experiences of **both** healthcare professionals and patients/public/community members who have experienced this way of working. This includes, healthcare professionals and patients/public/community members working together as team members, or patients/public/community members leading or being involved to improve healthcare design or delivery.

We will be conducting semi-structured interviews, over the phone, skype or in person (where feasible), which will last no longer than 1 hour.

Please note, we are excluding initiatives that have used Experience-Based Co-Design, due to research which is already being carried out to explore this method.

If you would like to share your experiences, or would like further information/have questions, please get in touch with Meerat Kaur,m.kaur@imperial.ac.uk.

Appendix H: Study information guide

Evaluation of the [Organisation name] Systematic Approach to translating evidence-based research into practice in healthcare

Information sheet for participants

The research is being conducted by a team at [university], based at [organisation] at [Hospital]. Before you decide whether you wish to participate in this research study please take your time to read the information so that you understand why this study is taking place and what it will involve. We will be very pleased to answer any further questions.

What is the purpose of this study?

While peer-reviewed clinical evidence (such as journal articles, guidelines, toolkits) describe activities that healthcare providers can undertake to improve healthcare, they rarely come with a blueprint for how it can be embedded in routine practice.

The [organisation] programme has developed a systematic approach consisting of additional tools and methods to help with this process of embedding research into routine practice in healthcare.

The purpose of this research study is to thoroughly assess the strengths and weaknesses of the systematic approach and its component parts, and to better understand "what actually happens" during the process of evidence translation and improvement.

The results of this research will be used to iteratively develop the approach and scale up improvements nationally and internationally.

Why have I been chosen, and do I have to take part?

You have been identified to take part due to the role you play in healthcare delivery, improvement or research. This could be as an academic, NHS staff member or member of the public. In addition you or your organisation is involved in a collaborative programme of healthcare improvement and research.

Participation is entirely voluntary. If you decide to contribute to a part or the whole of this study, you will keep this information sheet and sign an informed consent form before any interaction with the research team takes place. You can choose to withdraw from the study at any point without giving any justification and all data relating to you will be permanently destroyed.

What will the study involve?

There are two ways to be involved in this research study, either as a part of a [organisation] Quality Improvement team, or as an individual involved in Quality Improvement in healthcare. For either of these ways, you may be invited to participate in some of the following activities:

Interviews: Interviews will take place between one participant and a researcher and will explore a set of semi-structured interview questions and will take 30 – 90 minutes to complete. Participants may be asked to undertake more than 1 interview (up to 4) and participation in any additional interviews is entirely voluntary.

Focus groups: Focus groups will take place between one to three researchers and a small group of research participants (up to 30) and will explore a set of semi-structured questions posed to the group. Participants may be asked to undertake more than 1 focus group (up to 4) and participation in any additional focus groups is entirely voluntary.

Due to the longitudinal nature of quality improvement work and the many topics involved, you may be invited to participate in up to 4 interviews, and/or up to 4 focus groups. The number of interviews or focus groups will not be directly related to your level of involvement with [organisation]. You are welcome to participate only in those interviews and/or focus groups which are of interest to you. You are free to decline contact for additional opportunities; this will be noted and researchers in this study will not contact you for further interviews or focus groups.

Observation of [ORGANISATION] meetings and training events: If you attend [ORGANISATION] meetings or training events, for [ORGANISATION] project teams, steering groups, fellowships, and/or the Exchange Network, a researcher may take notes about these events to enable investigation of engagement, facilitation and training in the systematic approach; fidelity of use of the systematic approach; individual perspectives and contextual factors. These observations will be general and will not include any patient-identifiable information, and access to the notes will be available only to approved researchers.

Event questionnaires: If you attend [ORGANISATION] training events or facilitated workshops, you may be asked to fill out a brief anonymous survey about the event. These questionnaires will be used for both operational purposes to improve support for your Quality Improvement projects, and for research purposes to explore effective methods of training and facilitation, individual perspectives, and contextual factors. The number of questionnaires you are asked to fill out will be related to the level of your involvement with NIHR [ORGANISATION] and the number of training events and materials you access. You are free to access these materials and training events without answering the questionnaires or participating in this study.

Documentary analysis of [ORGANISATION] Quality Improvement Projects: Documents produced through the routine delivery of [ORGANISATION] Quality Improvement project are owned by the [ORGANISATION]programme and may be used for research purposes. For example, Process Mapping is an exercise which Quality Improvement Projects will undertake as part of the systematic approach. Outputs of Process Mapping exercises may be analysed to determine the usefulness of the exercise in delivering healthcare improvements. Researchers are also interested in observing meetings that take place between different individuals regarding planning, delivery or evaluation of improvements in healthcare. This means that at some meetings which are scheduled to take place as part of existing programmes of work, researchers will ask permission to audio or video record meetings. This will only take place if all involved in the meeting consent to this happening. In other meetings, researchers may take observations either as participants in the meeting or as non-participant observers. These notes may be used for research purposes to determine the strengths and weaknesses of the systematic approach, as well as to explore different perspectives in healthcare improvement. For each Quality Improvement project, the clinical lead or [ORGANISATION]Fellow leading the project will be responsible for communicating that documents produced by the team and observations at meetings may be used for research purposes.

What will happen to the results?

A report from this work will be provided to funders ([organisations]) and may be published. Results from this research will be published in peer-review scientific journals and conferences. Findings will also be fed back to those involved in healthcare improvement and research programmes to inform their future work.

Confidentiality

Data produced from this research will be stored securely according to the Data Protection Act. All information including audio recordings and transcripts will be kept confidential and access will be granted to authorised members of the research team only. If any quotes are used in reports or publications these will be anonymised and at no time will information be identifiable to specific individuals. Ten years after completion of the study all personal and research data will be destroyed.

In the case of serious misconduct/malpractice being revealed during an interview or focus group, issues will be discussed with an individual’s line manager and if necessary escalated through appropriate Trust or University procedures.

What if there is a problem?

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone’s negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator ([name]). The normal National Health Service complaint complaints mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial AHSC Joint Research Compliance Office.

Who has reviewed this study?

The research for this study was externally reviewed in order to receive funding for the NIHR [ORGANISATION]programme 2014-2018 and/or the competitive Health Foundation Improvement Science fellowship. The full study was reviewed and approved by the [university] Joint Research Compliance Office and the NHS Health Research Authority.

Who is organising the study?

This study is organised by the NIHR [ORGANISATION] programme which operates in [university], [hospital], and [hospital]. Contact details for the Research Portfolio Coordinator for the NIHR [ORGANISATION]programme can be found below.

What are the benefits of joining this study?

Participation in this research will provide an opportunity for reflection and engagement in dialogue about the process of evidence translation and how this can lead to improved patient care.

Contact Details [removed]

Appendix I: Consent Form

Evaluation of the [organisation] Systematic Approach to translating evidence-based research into practice in healthcare

Please read and confirm your consent to participate in this study by initialling the appropriate box(es) and signing and dating this form. Please inform the researcher if you would like your own signed copy of this form for your records.

1. I confirm that the purpose of the study has been explained to me, that I have been given information about it in writing and read it, and that I have had the opportunity to ask questions about the research and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary, and that I am free to withdraw at any time without giving any reason and without any implications for my legal rights. ☐
3. I give permission for the interview to be audio-recorded by the researcher, on the understanding that the recordings will be kept in a secure locked cabinet and/or secure password protected computer server and destroyed one year following the end of the study. ☐
4. I understand that anonymised quotes may be used in publications stemming from the research but not in any way that might allow for identification of individual participants. ☐
5. I understand that all personal and interview data will be kept confidential at all times and accessed only by approved researchers ☐
6. I agree that my details, including personally identifiable details, may be kept on Imperial College London computer systems/premises ☐
7. I agree that my research notes/data may be accessed by responsible persons from the Sponsor, NHS Trust, or regulatory authorities, in order to check that the research has been conducted correctly ☐
8. I agree to take part in this study. ☐

________________	__________	__________________
Name of respondent	Date	Signature
________________	___________	_________________
Name of researcher taking consent	Date	Signature

Appendix J: Deductive coding framework

Name
Value
Cost
Benefits
Value co-creation
Dialogue
Access to information
Reflexivity
Transparency
Roles for citizens in public sector co-creation
Role for healthcare professionals
Partnership synergy
Resources
Partner characteristics
Relationships among partners
Partnership characteristics
External environment
Inductive coding
Power
Spaces
Use of QI methods
Elision of PPI and QI
Thick descriptions
Methodology

Appendix K: Sample coding report

Name		Sources	References	Created On
Value		56	344	25/08/2017 19:48
Cost		32	119	25/08/2017 19:49
Emotional cost		4	21	06/10/2017 13:33
To PP		4	13	29/06/2018 21:41
HCP		1	1	01/07/2018 14:28
Tension between HCP and patients		9	13	29/06/2018 21:14
Co-destruction		1	1	05/01/2018 16:28
HCP receive brunt of anger		1	2	05/01/2018 16:52
Seeing HCPs as part of the system		1	1	05/01/2018 16:51
Outcomes of...		0	0	10/07/2018 10:04
Tension reduces chances of other PP getting involved		1	1	01/07/2018 20:11
Learning from tension or conflict		1	1	10/01/2018 14:52
Tension between different HCP escalated		4	4	02/10/2017 09:31
Wrong patient on team Co-destruction		5	6	05/01/2018 16:32
Tension from the patient - seen as less constructive		2	2	24/12/2017 00:08
They challenge		1	2	10/07/2018 12:03
Economic cost		7	18	30/06/2018 12:47
For organisation		2	3	30/06/2018 13:31
Face to face meetings		2	3	30/06/2018 13:36
For PP		5	10	30/06/2018 13:31
Physical spaces & costs met by patients		1	2	01/12/2017 20:29
Process to claim is too labourious to bother		1	1	29/11/2017 18:31
The more you are involved in the greater the cost		1	1	05/12/2017 13:45
Unmet travel costs for PP		1	2	30/06/2018 12:49
Patients more considerate of how much they spend on travel		1	2	30/06/2018 12:49
Payments being stopped		1	1	07/01/2018 10:43
Should be paid if on committee with others getting paid		1	1	06/07/2018 22:40
Influence of economic cost on perceived value of PP		3	5	03/07/2018 22:03
Patients seen to hold less value than HCP		1	2	05/01/2018 21:24
People don't value something free		2	2	04/10/2017 11:04
HCP not valuing unpaid patient		1	1	05/12/2017 14:30
Extra work		5	10	30/06/2018 14:13
For HCP		1	4	30/06/2018 14:13
Hard work		1	1	30/06/2018 14:13
Additional to day to day work		1	3	30/06/2018 14:18
For PP		3	4	30/06/2018 14:14
Need to be trained to then engage other patients		0	0	30/06/2018 13:22
To be able to engage with other patients		2	2	07/10/2017 08:52
Travelling to their location is difficult		1	1	01/07/2018 12:50
Demand on them increases the longer they are part of the intiative		1	1	01/07/2018 14:02
Tension		1	2	01/07/2018 20:08
Tension between HCP &PP because of workload		1	1	01/07/2018 20:08
By patient being selective with what they do or don't		1	1	29/06/2018 21:17
Time		26	44	01/07/2018 14:05
For HCP		16	24	30/06/2018 13:52
Patient engagement takes or consumes time		1	2	30/06/2018 14:11
Takes time away from day to day patient care		2	2	30/06/2018 14:23
No time		15	19	04/07/2018 09:18
Don't have time		4	4	19/12/2017 10:56
Extra time		1	1	30/06/2018 14:25
Lots of other things to do		1	1	30/06/2018 12:58

Appendix L: Permission to use Ramaswamy and Ozcan's work

Dear Meerat:
Thanks for your interest in our work.
Yes, you have our permission to use the said figure below.
Please do send us a copy of your thesis, as well as its citation.
All the best,
Venkat
****

Venkat Ramaswamy
Professor, Ross School of Business
www.venkatramaswamy.com

Permission granted for the use requested above:

I confirm that I am the copyright holder of the extract above and hereby give permission to include it in your thesis which will be made available, via the internet, for non-commercial purposes under the terms of the user licence.

Signed: Venkat Ramaswamy

Name: Venkatram Ramaswamy

Organisation: Ross School of Business, University of Michigan

Job title: Professor

On Dec 5, 2018, at 1:33 PM, Kaur, Meerat <m.kaur@imperial.ac.uk> wrote:
Dear Profs Ramaswamy and Ozcan
I am completing my PhD thesis at Imperial College London entitled 'Realising value through public-healthcare professional co-creation for service improvement'.

I seek your permission to cite and use the related diagram in my thesis from: "What *is* co-creation? An interactional creation framework and its implications for value creation". I would like to quote a number of parts as this is the framework I am using for my thesis, which I adapt to how patients/public and healthcare professionals interact when they are working to improve healthcare systems. The diagram I would like to reproduce is on pp.201.

I would like to include the quotes and the diagram in my thesis which will be added to Spiral, Imperial's institutional repository http://spiral.imperial.ac.uk/ and made available to the public under a Creative Commons Attribution Licence.

If you are happy to grant me all the permissions requested, please return a signed copy of this the e mail text after my signature. If you wish to grant only some of the permissions requested, please list these and then sign.

Happy to address any further questions you may have.

Kind regards

Meerat Kaur